ADSS Cymru
Yn arwain Gwasanaethau
Cymdeithasol yng Nghymru
Leading Social Services in Wales

Rapid review of how unpaid carers' rights have been upheld during and after the Covid-19 response

Association of Directors of Social Services Wales

Sue Revell, Ceri Breeze, Helen Mary Jones, Brian Meechan

June 2023

Contents

1. Introduction

1.1 In June 2022, the Senedd’s Health, Social Care and Sport Committee published the report of its inquiry into hospital discharge and the impact on patient flow through hospitals. It recommended the Welsh Government should review whether carers’ rights under the Social Services and Wellbeing (Wales) Act 2014 are being breached because of having to take on more caring responsibilities than they may be willing or able to due to lack of available services.

1.2 The Welsh Government asked the Association of Directors of Social Services (“ADSS”) Cymru to lead the review. The review is part of broader work by the Chief Social Care Officer to review the quality and effectiveness of carers’ needs assessments.

Social Services and Well-being (Wales) Act 2014

1.3 The Social Services and Well-being (Wales) Act 2014 defines a carer as a person who provides or intends to provide care for an adult or a disabled child. That Act states that in general, professional carers who receive payment should not be regarded as carers for the purposes of the Act, nor should people who provide care as voluntary work. However, a local authority can treat a person as a carer if they consider that, in the context of the caring relationship, it would be appropriate to do so. A local authority can treat a person as a carer in cases where the caring relationship is not principally a commercial one.

1.4 The duty is triggered if it appears to the local authority a carer may have needs for support. The duty of assessment applies regardless of the authority’s view of the level of support the carer needs, their financial resources, or the financial resources of the cared-for person.

1.5 Carers have an equal right to assessment for support to those who they care for. A local authority must offer an assessment to any carer where it appears that the carer may have needs for support. It must assess whether the carer has needs for support (or is likely to do so in the future) and if they do, what those needs are or are likely to be.

1.6 The assessment must include an assessment of the extent to which the carer is able and willing to provide the care and to continue to provide the care, the outcomes the carer wishes to achieve both in terms of themselves and, if a child is the carer, the outcomes the person(s) with parental responsibility for that child wish(es) to achieve for them and the extent to which support, preventative services, or the provision of information, advice or assistance could assist in achieving the identified outcomes.

1.7 The assessment must also have regard to whether the carer works or wishes to work and whether they are participating or wish to participate in education, training, or leisure activities. If the carer is aged between 16 and 25, the assessment must include an assessment of any current or future transitions the carer is likely to make into further or higher education, employment, or training. If the carer is a child, the assessment must have regard to their developmental needs and the extent to which it is appropriate for the child to provide care.

1.8 The assessment process is set out in Part 3 of the Code of Practice.

Funding for unpaid carers

1.9 Support for unpaid carers is funded in a variety of ways. Sources include the budgets of local authorities and additional grants from the Welsh Government. The grants include:

- £4.5 million for the Carers Support Fund until 2025.
- £9 million between 2022-2025 to establish a national Short Breaks Scheme. Carers Trust Wales was appointed to deliver the scheme and is working collaboratively with Regional Partnership Boards, local authorities and the third sector. Part of this funding has been used to set up a third sector grant scheme entitled “Amser”, which commenced in April 2023.
- £29 million announced in April 2022 to provide unpaid carers who were in receipt of Carers Allowance with a £500 payment. This was a one-off payment in response to the rising cost of living.

2. Approach

2.1 The key aims of the review were to assess:

- How the needs of unpaid carers are being met by local authorities and their commissioned partners considering the ongoing impact of Covid 19.
- How the rights of unpaid carers under the Social Services and Well-being Act are being upheld.
- Any ongoing impact of the pandemic on unpaid carers in need of statutory support.

2.2 Engagement with unpaid carers was a core feature of the review. It was supplemented by interviews with staff in local authorities. This enabled matters to be considered from different perspectives. The Welsh Government selected seven local authorities to participate in the study.

2.3 Information was gathered using a variety of methods:

- Face-to-face interviews
- Telephone and online interviews
- In-person focus groups
- Online focus groups and meetings
- Online survey

2.4 An online survey was not part of the original plan but was developed after practical difficulties for unpaid carers attending focus groups in person and online were identified. The brief survey, which was available in English and Welsh, enabled significantly more unpaid carers to give their views and to share their lived experience during and after the pandemic.

Response

2.5 Feedback was obtained from:

- 25 semi-structured interviews with officers in seven local authorities.
- 66 unpaid carers via in-person focus groups and online focus groups.
- 302 unpaid carers who responded to the online survey.

2.6 Of the 302 unpaid carers who responded to the online survey, 27 were aged under 18, 7 were aged between 18 and 25, and 268 were older than 25.

Acknowledgement

2.7 The authors wish to thank the staff in local authorities who took time to give their views, and the substantial number of unpaid carers who participated in focus groups or who responded to the online survey. Their willingness to share their experiences means the review has been able to explore in depth the challenges and difficulties carers face day to day, some of which are significant. Special thanks are due to the staff of CREDU, a third-sector provider operating in mid, west, and north Wales for their perspective and their help in arranging some of the in-person and online focus groups.

3. Local authorities' perspectives – impact of Covid-19

3.1 This chapter considers the impact of the Covid-19 pandemic on unpaid carers, young and old. It is structured around the following themes:

- (i) The impact and/or disproportionate impact of Covid-19 on unpaid carers or young carers, and those with protected characteristics.
- (ii) New ways of working to support unpaid carers and young carers because of Covid-19.
- (iii) Any ongoing impacts of Covid-19 on unpaid carers and young carers.
- (iv) Steps taken to mitigate any ongoing impact(s) of Covid-19 on the provision of services to unpaid carers and young carers.

3.2 While the impact of Covid-19 was similar for all local authorities, there is some variation in action taken to manage and deliver support during the pandemic and after it.

3.3 Local authority officers' views are based largely on the experience of carers known to them and to others who have come forward or been identified after the pandemic. They are acutely aware that many people who provide care do not identify or think of themselves as carers. There are also others who, for a variety of reasons, do not wish to engage with social care services.

Impact of Covid-19 on unpaid carers

3.4 Unsurprisingly, the consensus is that Covid-19 had a significant impact on carers, many of whom were vulnerable due to age or other factors. The difficulties in providing support e.g., shortage of domiciliary care workers, working restrictions, and the closure of services, increased the demand and pressure on unpaid carers. In some cases, this was due to carers stopping in-person support such as domiciliary care due to concerns about catching Covid-19.

3.5 Some interviewees could not say with certainty if Covid-19 had a disproportionate impact on unpaid carers although most concluded it had. Their isolation was compounded by the closure of services in lockdown, meaning they needed to do more for the adult or child they cared for, sometimes without any support and/or respite if they were receiving any. This was true when day centres were closed and when children, particularly those with autism and other complex needs, could not attend school. Local authorities reported receiving calls from carers who had been "pushed to their limit". Some individuals simply wanted someone to talk with and to listen to them.

3.6 Carers with protected characteristics were sometimes affected to an even greater extent e.g.,, additional pressures to care for someone on top of their need to manage their own condition or disability. Carers and people who are cared-for who are deaf or who have hearing loss were particularly affected and one local authority reported a powerful challenge from the deaf community about not meeting their needs during the pandemic and, to some extent, before it. For some people with ethnic minority backgrounds who could not speak English, while they might had been supported by another member of their community at meetings, this was not an option during lockdown.

3.7 Aside from the direct health effects of the virus, the main impacts on unpaid carers were:

- Social isolation and loneliness, compounding the extra burden of caring, with many having to cope entirely on their own.

- Mental health concerns caused or exacerbated by measures such as lockdowns and service closures, which removed any support available to help carers cope, respite etc.

- Financial and economic impacts due to lockdowns and impact on jobs, and poverty e.g.,, no school meals provided because of school closures.
- Young carers becoming withdrawn and/or experiencing lower mood from being at home caring all day.

- Deterioration in the condition(s) of cared-for people e.g.,, mobility, cognition, after so long at home, which increased the care needs and pressures on unpaid carers.
- Some carers with protected characteristics were hit doubly hard, with concern for their own health and that of the individual(s) they were caring for, especially for those who also had to work.

- Delays in assessments; people asking for a face-to-face assessment had long waits for an assessment, although many teams kept in touch with them until the assessment took place. Assessments undertaken by telephone or via a virtual meeting were more difficult and not as personal.

3.8 On a positive note, there was more interaction with some carers during the pandemic. For example, weekly welfare calls by telephone or by socially distanced doorstep visits were common. Some people came forward for help having identified and/or recognised themselves as unpaid carers for the first time. This was sometimes the result of their isolation and the immense pressure they were under.

3.9 The rapid move to digital solutions e.g., online support; virtual carers' groups, also proved positive for some carers. That said, there is a view the digital divide in society widened, particularly in communities where digital poverty was already a major issue. While it accelerated digital capability and access for many, the inability to do this was a barrier to them receiving support delivered online.

3.10 Councils did their best to respond to needs as quickly as they could but could only respond to needs of those of whom they were aware. Many unpaid carers, including some with protected characteristics, were not engaged with services and so would probably have been disproportionately affected.

3.11 Fear was an outcome of the pandemic. During and even after lockdowns, many carers did not want to people to visit their houses. It was common for packages of care to be rejected. Similarly, carers were reluctant to venture outside because of concerns about the vulnerability of carer-for persons and risk of infection. This, combined with service closures, prevented them from receiving support, particularly respite.

3.12 Overall, the burden of caring, which was considerable for many carers before Covid-19, increased significantly. Many had to cope entirely on their own. In some cases they were supported by family who were furloughed or able to work from home who took on more themselves because they did not want different carers visiting each day. However, now back at work, not all family members can provide the support.

New ways of working because of Covid-19

3.13 The response of local government to the pandemic, a highlight of which was the rapid transformation of working practices to deliver alternative forms of care and support, is well documented. Services and support for unpaid carers – young and old – was an important part.

3.14 The pandemic challenged many traditional ways of working, particularly in communicating with carers and young carers. It caused local authorities to think differently and "out of the box". One interviewee said the postal service was originally a big part of the local authority's service and support. The fact nothing could be posted forced a move to other means, including email, social media, and new platforms for conversation and obtaining feedback. A variety of new approaches and ways of working were developed and implemented at pace. Some action was specifically for unpaid carers while they were also helped by other developments targeted at cared-for people.

Examples of new ways of working for unpaid carers in response to Covid-19

- Social work teams and other staff undertaking welfare calls with carers by phone instead of visits, and increased telephone support to keep in touch e.g.,, weekly contact. More proactive contact to help vulnerable people instead of a typical reactive approach pre-pandemic.
- In-person contact within restrictions e.g., doorstep or distanced chats.
- Fortnightly check-in with people online or via channels such as WhatsApp.
- Telephone advice lines.
- Outreach work by some day centre staff.
- Groups and clubs for carers and young carers via virtual meetings online and activities such as bingo nights, quizzes, virtual coffee mornings.
- Kits sent out e.g., well-being packs, and for certain activity-based clubs e.g., building block kits; jewellery kits; colouring kits etc.
- Vulnerable Pupils Panel, which allowed consideration to be given with a third-sector organisation to action for young carers who were hard to reach.
- Stationery and puzzles for young carers to help them feel valued and appreciated.
- An online animation as a resource for schools to help young people self-identify as carers.
- Arrangements to provide some people with food and/or access to shopping, including purchasing food for carers who had special dietary needs (public funding and in some cases, from public donations).
- Worked with the police to develop a Covid-19 pass so parents with a child with autism could take them out e.g., to a park, without problems caused by travel restrictions.
- Newsletter to keep carers up to date with support available, including notification of priority groups for carers to receive vaccinations, and communications, issued via email and social media.

3.15 Some responses to the pandemic were bespoke to certain groups of carers e.g., young carers. One local authority said food banks were available but young carers were not necessarily confident enough or their self-esteem was too low to use them, so youth workers delivered school meals to homes. Some young carers were also given a letter from the Director of Social Services to be able go shopping in "Key worker" access time. A Carer's ID Card was also developed to help carers and helped them to address challenges to why they were out during lockdown.

3.16 The limitations of some of the new ways of working are recognised. Some cannot fully substitute for face-to-face support e.g., day centres; day services; in-person support groups, as means of respite. However, the alternatives helped many carers to cope with lockdowns and continue to help, as evidenced by their continuation e.g., online meetings. While the pandemic had many negative impacts, there were some positives. Some people who did not attend face-to-face groups and meetings pre-pandemic now participate in online meetings because of Covid. Some disabled people found online meetings easier to access. Online meetings have also opened opportunities for people in rural areas and others who might experience difficulties in attending meetings for transport reasons.

3.17 Digital activities did not work for everyone. Reasons included a lack of equipment (e.g., computer, tablet), a lack of knowledge of how to access online platforms and, particularly in parts of rural Wales, poor broadband connectivity. Tablet computers and laptops were given or loaned to many people with training on how to use them e.g., one local authority mentioned a grant from Digital Wales which provided 15-20 laptops plus access for young carers. Another local authority said the laptops they issued were kept by the young people who received them.

3.18 Between lockdowns and as restrictions were lifted, some local authorities prioritised the re-opening of services for carers. In practice, this has often resulted in a hybrid approach with a mix of physical and virtual meetings. Feedback suggests it has taken some time for face-to-face sessions and groups to resume and in some cases, provision has not reopened or has not returned to the same pre-Covid level. Since the pandemic, resources e.g., information and advice, provided via digital means have increased significantly.

Ongoing impact of Covid-19

3.19 The Covid-19 pandemic is officially over, and many aspects of day-to-day life have returned to normal or near normal. However, local authority staff recognise there are legacy effects for unpaid carers and ongoing impacts. The main ones are:

- Impact on individuals’ health and well-being of the pandemic e.g., when regular health services and treatment was not available.
- Impact on young carers’ mental and emotional health and well-being due to isolation for long periods, and on their education. Many are still anxious about attending school. One authority reported increased in the number of young carers they are supporting who have chosen to be educated at home.
- Ongoing anxieties about Covid-19, which for some carers still means a reluctance to go out and participate in support activates.
- Lack of access to some services and/or changes in service configuration e.g., opening times, capacity. This includes GP and other health services in addition to social care services, such as day centres.
- Backlogs in assessments and the consequent impact on people having to wait, or wait longer, to receive support.

3.20 The availability of day services e.g., day centres, was a common theme. Some local authorities have been considerably more cautious than others about re-opening services and support after lockdowns. Some services are still not open or are not running at pre-Covid capacity. The impact of day centres not reopening is recognised, particularly as there are reports of more carers seeking respite care and support. It was outside the scope of this study to capture a detailed picture but from discussions, it is fair to say the picture is mixed. The ability to provide domiciliary care services is a common problem.

3.21 Several officers reported increased demand for support since the pandemic. Some is said to be the result of changes in the carer’s ability to continue providing care due to their own health or a deterioration in the condition of the person they care for, with needs becoming more complex and with some cases reaching crisis situations. In some cases, this, and a lack of domiciliary care, has resulted in more older people having to go into residential care.

3.22 Backlogs have accumulated because of the services e.g., assessment, being unavailable or substantially compromised by being unable to have face-to-face contact because of lockdown restrictions. There were some reports of a surge of people all needing similar support.

3.23 Several examples were offered on the impact of the pandemic on individuals receiving health and/or social care and support and which continue to affect them or the people who care for them. The main impacts were:

- Individuals not being seen by services resulting in further deterioration in their condition e.g., physical condition; memory.
- Deconditioning of individuals over the time of the pandemic and its lockdowns e.g., individuals who have not left the house for 2+ years, meaning they are relying more and more on family carers who no longer have the capacity to support now back to work.
- Sense of abandonment, loss of identity, fear of being forgotten.
- Cases of long Covid in the cared-for and unpaid carers.
- Impacts on carers' mental health and wellbeing from having to stay at home and often becoming even more isolated than they were before the pandemic.

3.24 One interviewee highlighted an issue which is often overlooked, namely the effect on carers who lost loved ones because of, or during, the pandemic. They often do not know what to do with themselves and need after-care support to deal with risks associated with grief and loss. One authority is addressing this with third sector partner organisations to develop information and support options when they are ready e.g., return to work, volunteering, activity programmes, social prescribing. It is felt this type of support would benefit from being highlighted by a supportive message from the Welsh Government.

3.25 Many parents were unable to support their children with education during lockdowns. Young carers are thought to be even more affected as parents just could not help. There are reports of gaps in education. Many young carers became used to being at home and some preferred it. Some have struggled or still struggle with the emotional and mental health aspects of returning to school, which has been difficult e.g., increased attachment, over reliance of parents on the young carer, young carers not wanting to leave parents, fear of bullying etc.

3.26 Anxiety is manifesting itself in a variety of ways. Despite the pandemic being declared over, there remains some general anxiety and fear around Covid-19. Some people feel Covid-19 is not disappearing and are still worried about it. They have a strong sense of wanting to protect themselves and have significant residual anxiety about engaging and mixing. This can cause barriers to carers getting out and about because do not want to put the person they care for at risk, or a preference to participate in small face-to-face sessions as opposed to larger gatherings. It can also present challenges for service delivery. Some young carers are still worried about attending school because of the risk of taking the virus home.

Case studies:

A family needs carers to cope with both young adults in the family who have life-limiting disabilities. Their mum is anxious about having people in and out of the house and wants

> *staff to live in the house in 2 -week blocks. While this would be ideal for the family, it is not possible from a staffing position.*
>
> *One young carer still won't leave the house for fear of catching something and giving it to their really poorly mum. Help is being offered outside the house as they are resistant to allowing people in to help.*

3.27 While this report considers the impact of Covid-19, the increasing cost of living was frequently mentioned, particularly utilities such as heating, which often have a disproportionate impact on people who are vulnerable for health or other reasons. For many unpaid carers, the cost of living has overtaken Covid-19 as a source of concern and worry. One interviewee cited reports from a third sector provider receiving more calls from carers worried about bills, and Citizens Advice reporting increased calls about debt management.

Steps taken to mitigate the ongoing impact of Covid-19

3.28 All local authorities said they are taking action to try and mitigate the ongoing impact of the pandemic. Some ways of working introduced to manage the pandemic are continuing while others have returned to pre-pandemic arrangements. Hybrid working e.g., combinations of telephone and online meetings in addition to face-to-face meetings, is common. Action can be grouped under three broad headings:

(i) Dealing with backlogs.
(ii) Communication – information and contact.
(iii) Support for carers.

Backlog

3.29 Much is being done to catch up with the backlogs of assessments which accumulated because of restrictions on working practices and changes in staff deployment e.g., in one local authority, the Carer Assessment Team weas redeployed to undertake well-being calls on people who were receiving packages of care. Capacity was also affected by staff being off work with Covid, and recruitment and retention issues, the impacts of which are continuing.

3.30 Not all local authorities report a waiting list for carers' assessments. Where there are, action varies. For example, one local authority has contracted out its assessments to a third sector organisation and reports positive feedback. Another is training staff from other teams to do well-being assessments, with staff helping them to have "what matters" conversations. It has also developed a visiting service where staff have been given additional training to help them identify additional carer needs and allowing them to fast-track cases direct to social workers. One local authority reported a dramatic effort has reduced its waiting list from 90 to 30.

Communication

3.31 The more varied methods of communication developed during the pandemic are continuing. In some cases, this is alongside the return of pre-pandemic, and typically traditional, means of communication such as post. In one authority, the use of email has continued monthly, which means carers are receiving more information on a regular basis. Another said it has increased email contact to 3 magazines, 3 newsletters, and 3 bursts of information instead of relying only on postal means. Letters are still used for matters considered important. More use is made of social media and its website, with new web pages and web links e.g., regional website connects into local authority site, and links to the commissioned provider's website.

3.32 Another local authority has maintained an Advice Line set up in the pandemic and is working to reach and support more people. Telephone contact has also been continued by one local authority, which means they are able to do more by not relying solely on face-to-face contact. The benefits of mixed methods of contact were recognised during the pandemic. Some people prefer the privacy of telephone or video calls rather than visits to their home.

Support

3.33 Most local authorities now have some form of hybrid provision. Examples include a return to face-to-face meetings in some areas while at the same time continuing with meetings online. This allows a degree of choice for carers. Some carers are very keen to return to face-to-face contact while others, particularly where they have anxieties, are content to continue with online meetings. Outreach work has also continued where day centres remain closed. Some local authorities are working with their neighbouring authorities to try and ensure no young carers fall between gaps in support.

3.34 It is recognised that transport problems and reduced public transport has an impact on people's ability to attend meetings, particularly in rural areas. In some cases, online meeting is the only option. It is fair to say that without Covid-19, carers would not have had a choice. Ironically, it could be argued that in some ways, the pandemic has helped the "choice" aspect of the Social Services and well-being (Wales) Act 2014.

3.35 Since the pandemic, several local authorities have commenced new developments, examples include "Well-being hubs", which will change the day service model, and the development of an online self-help toolkit aimed at carers. These would not have happened without Covid-19. Improvements to training have also been made in one authority so anyone who works with families has an eye to the bigger picture and the needs of all those involved, including carers and young carers. Some local authorities have also consulted on changes e.g., regional review of respite care; respite/day service offers via different weekly activities instead of "away" time. One local authority reported an extensive programme of engagement on respite care in communities which resulted in more than 700 responses.

----

4. Local authorities’ perspectives – needs and rights

4.1 This chapter considers what local authorities are doing to meet the needs of carers and young carers and how they are upholding their rights under the Act. Discussion areas were:

(i) Action to meet the needs of unpaid carers, including young carers.

(ii) Extent to which carers’ rights under the Social Services and Well-being (Wales) Act 2014 are being upheld.

(iii) Instances when a carers’ rights could not be met or where there were problems in meeting their needs.

(iv) Any differences in meeting the needs of older carers and young carers.

(v) Areas where performance is felt to be falling short of what carers are entitled to under the Act.

(vi) Barriers which prevent effective support to unpaid carers and young carers.

4.2 Inevitably, there is some crossover between themes. Many are interrelated.

Meeting the needs of carers and young carers

4.3 The overall impression gained from discussions with staff in a variety of roles linked to carers and/or young carers is one of commitment and proactivity in trying to meet their needs. The limitations of what can be done are recognised, with resources, including staff recruitment and retention, frequently cited as barriers.

4.4 Before needs can be met, carers must be identified. Local authorities use their services and channels, including some third sector organisations, to identify unpaid carers. For adult carers, they also rely on GPs and the NHS. For young carers, schools and colleges have a significant part to play.

4.5 Some local authorities believe they are good at meeting the needs for information and advice and, where there are no waiting lists, for assessment. However, waiting lists for assessments were common as well as challenges in providing support after assessment. The pandemic triggered the rapid development of many new approaches and developments in practice, which would probably not otherwise have happened. Building on the experience, all local authorities recognise they can do better and improve and are acting.

4.6 Reaching out to carers with information to help them in their role and to raise awareness of their rights and support was a common theme. The following pages summarise action being taken in one or more local authority areas. The action varies, often reflecting the way services are organised, the make-up of the population, and geographical issues such as rurality.

4.7 The precise organisation and levels of resource vary but most local authorities have dedicated members of staff or teams who are responsible for reaching out and identifying carers and supporting and liaising with other teams in front-line services and social workers in Adult Services and Children’s Services. Usually, there are separate teams for adult carers and young carers.

Young carers

4.8 Young carers are identified in a variety of ways but reaching out to them in schools, colleges and via youth settings is the most common approach, supplemented by identifying them via community services and settings e.g., Family Centres; Well-being Hubs, third-sector organisations, and via statutory services. Identifying a young carer and them recognising and accepting their role is preceded by information and awareness-raising. It can take time. There have been considerable efforts to identify young carers by working with schools and colleges and this is continuing. One interviewee emphasised the prime role youth services and education have in identifying young carers, which is the foundation for being able to uphold their rights.

4.9 The precise process for assessment of young carers also varies in terms of how, when and by whom. The latter included in-house social care staff or contracted third parties, which are usually third sector organisations with relevant experience of working with young people. The variety of processes are not described in this report, which focuses on initiatives and services designed to identify young carers and meet their needs. The experience of Covid-19 has added to the range of initiatives to help young carers.

4.10 Action common to helping young carers includes written information, emails, social media and young carers' groups and fora. In some cases, young carers are helped to attend groups by transport being provided or by subsidised transport, sometimes for limited periods to allow attendance over several weeks. Some of the groups make use of online meetings, which can help young carers in rural area or areas without sufficient public transport services. Online groups are also known to help young carers who are still anxious about in-person meetings due to worries about bring Covid-19 back into their home.

Examples of action by local authorities to meet the needs of young carers

- Outreach into secondary schools and colleges, and in at least one area, primary schools, to identify children who are providing care to a family member or sibling.
- Young Carers Card - originated from need for young carers to be able to identify themselves during the pandemic e.g., being challenged for being in a supermarket. Developed with young carers. Has extended to include things such as discounts.
- Young Carers in School policy with guidance for school staff.
- Work with a college to help them create flexibility in timing of learning opportunities for young carers.
- Offering more family-based activities which involve young carers and their parents, which has received positive feedback.
- Young Carers Support Grant – uses include short breaks, access to gyms/fitness, home goods, supermarket vouchers.
- Carer Awareness training for social workers to ensure they are up to date in promoting carers assessments (which is also relevant to adult carers).

4.11 When identified, young carers are supported in several ways e.g., by youth workers, outreach workers, social workers, and third sector organisations using a variety of methods including 1:1 support, groups and activity sessions, online support, information, and advice.

The following description of different levels of services was provided by one of the local authorities:

Example of one local authority's approach to supporting young carers

- Level 1 support: information and advice: added to the master list for email communications e.g., information on groups and organised activities and/or opportunities, including launch of the Young Carers Forum launched in March 2023.
- Level 2 support: additional individual support needs identified: needs are linked to caring role e.g., self-confidence, managing difficulties at home, dealing with worries/anxiety about caring). Offered up to nine 1:1 session in school or in the community. Joint Assessment Framework used (which is similar to Families First but adapted to include detailed carer responsibilities).
- Level 3 support: statutory services: statutory cases checked to ensure they have active and adequate support from social care/children's services. Can also offer 1:1 support in addition to the Level 2 offering. May also work with parents in a holistic way.

4.12 Despite best efforts, local authorities know there are many children who perhaps do not see themselves as "carer", are not aware of their rights, and who have not yet come forward for support. One local authority said that when a young carer is identified, it is sometimes also possible to identify an adult who may need care and support but at that time is not receiving any. Where this is identified, a referral is made to Adult Services.

Adult carers

4.13 Like young carers, there is a wide variety of action taken by local authorities to identify carers. The precise details vary but examples include checks when someone contacts a front-line point of contact or social services about social care and support for a loved one, and a proactive approach to reach out to the people through a variety of channels in-person and through digital means.

4.14 The subsequent process of assessments and meeting needs also varies across local authorities but involves in-house staff or contracted providers. This report provides examples of initiatives and developments to meet carers' needs. It also highlights areas local authorities consider need to be improved.

4.15 The following are examples used by one or more of the seven local authorities covered by this review. It is recognised the practice of individual social care practitioners is important to the action taken and it is acknowledged there can be some inconsistencies in what is offered to carers.

Examples of action by local authorities to meet the need of adult carers

- Support groups run by a local authority, provider, or third-sector organisation e.g., in one area, an Autism Group has 40-50 organisations and community groups feeding into it, with parents/carers taking the lead and holding practitioners to account.
- Carer’s Pack sent out where appropriate after contact with front-line point of contact services and being asked about any caring responsibilities.
- When an assessment for a cared-for person is undertaken, a social worker makes the offer to a carer and then they, or another team, will undertake the carer’s assessment.
- An “Investors in Carers“scheme: carers are encouraged to register with their GP surgery, which gives them access to an assessment.
- Carer’s Information Service, which reaches out to unpaid carers encouraging them to self-identify and self-refer and provides regular information. In 2017 it had 500 people registered as unpaid carers and now has 2,000.
- Carers Outreach providing information and advice, helping carers to feel informed and updated. One local authority has around 920 carers on their books.
- Annual wellbeing days for carers to access information, advice, and activities.
- Carer’s Fund / Carer’s Grant – financial offer e.g., £150, to use in a variety of ways, which they chose, to help improve their own well-being. Simple application process. (Funded by the Welsh Government). In one area, 500 families are benefitting.
- Carers “Right to a Break” scheme for short breaks (funded by Welsh Government).
- “Employer for carers” scheme in one region and action in other areas. Promotes carer-friendly organisations e.g., where staff have more flexibility to undertake caring roles (in addition to flexible working). In one authority, 40 members of staff are carers.
- Counselling service offered in one area through a contract with a third sector organisation specialising in mental health and wellbeing.
- Carer’s Card – originated from need for unpaid carers to be able to identify themselves during the pandemic e.g., being challenged for being in a supermarket. Developed with carers. Has extended to include things such as discounts.
- Carer’s emergency card - carers complete a contingency plan, which is registered on an authority’s system, so the team can be contacted e.g., if the carer is unwell.
- Respite Grant Funding (funded by the Welsh Government) – issued in voucher format to allow a carer a break from the caring role. No criteria set, enabling choices relevant to personal circumstances i.e., what makes the most useful difference. Developed with unpaid carers.

Improvement

4.16 Local authorities recognise the need to do more to help unpaid carers. Several have developed or are developing or updating their strategies and/or action plans for identifying and supporting unpaid carers. Carers are involved in some of the work. The following are examples of improvements being made or being considered:

- Action to improve the relationship with carers; improving the carer's assessment using focus groups to understand the carer's journey and seeking feedback on the current process.
- Two local authorities have developed a more personal feel to their written communications and their carer networks and groups which, over and above being opportunities for learning, respite, and enjoyment, are seen as channels for co-production.
- Action to encourage unpaid carers to come forward sooner rather than later, and before their situation reaches crisis point. Identifying and supporting carers is a prevention and early intervention measure, which can save money by avoiding or delaying the need for statutory services.
- Reviewing terminology and language, which is thought might be a factor in why a carer refuses an assessment. Terms such as "assessing your capability" might make them feel it is an assessment of them personally and fear personal criticism. The response is often "I'd rather not get involved thanks". Changing the terminology and making the assessment more of a conversation might offer a quick win.
- Checks built into some systems e.g., an Adult Services assessment document asks if a Carer's Assessment has been offered and similar for mental health in the Care and Treatment Planning assessment document, and in Adult Services, the integrated assessment process which is embedded into the IT system.

4.17 Action is also being taken to mitigate the impact of problems e.g., delays in carers' assessments. One interviewee said the waiting list for social services surpasses anything they have seen in more than 25 years. Their team has talked to day centre managers to see if the Carer Assessment Team could offer people whose needs are already known an initial assessment while they are waiting for full assessment by a social worker. This is not to bypass the formal system but to offer some support while they are waiting for it. A trial is under way for a small cohort awaiting full assessment to give "respite by day centre". It is small but practical support which shows the carer has not been forgotten.

4.18 Two local authorities have questioned the number of unpaid carers they have helped or are helping by looking at their communities and their caseloads for care and support. One local authority has identified a relatively low number of carers from ethnic minority groups while another has said there should probably be a lot more carers on their list for assessment given the hundreds of people who are receiving care and support.

Opportunism

4.19 Taking advantage of service opportunities to identify unpaid carers was mentioned in a few discussions. Examples include calls to front-line or social care to seek care and support for someone who needs it; the person calling is asked if anyone is undertaking a caring role. A similar question is asked when an assessment is being undertaken for an adult. Often, problems and difficulties encountered e.g., the reasons behind a young person's attendance or performance at school, can be due to them providing care for a parent or a sibling. Being prepared to have conversations, listening, and inquiring were highlighted as important features of a good approach.

Case study:

Example of a gentleman, caring for a family member with dementia, asking for PPE during the pandemic. During the call he mentioned their increasing deterioration and their need to use more hygiene products, but he did not have sufficient bin capacity for disposal, so was travelling around the local authority area to utilise his daughters' bins too. The social worker contacted the waste department and asked for a bigger bin to be delivered. This happened because of an incidental conversation and the commitment to helping someone. Many citizens are unaware of what is available. Small things can sometimes make a big difference to people.

Upholding carers' rights

4.20 Two broad themes were discussed. The right to an assessment, an assessment being undertaken and, if eligible, action to provide the agreed support. Support may be provided by an in-house service or contracted provider, or by a direct payment which allows the carer to choose their support and how and when it is provided.

4.21 The other theme was identifying unpaid carers. Someone's rights as an unpaid carer can only be upheld if they can be identified in the first place. This is not necessarily straightforward. Not everyone caring for someone considers themselves a "carer" e.g., care for loved one as a husband or wife; a child who helps their mum or dad who has a health condition or disability. Furthermore, the "carer" label does not sit easily with everyone and neither does the idea of engaging formally with social services, which for some people has stigma. One local authority said a review showed that typically, more people decline rather than accept a carer's assessment. Common reasons are doing their duty as a partner and "not wanting a fuss".

4.22 The importance of identifying and supporting carers is recognised. Unpaid carers play a vital, often unseen, and undervalued, role in the care system. A carer's health and wellbeing are important. If they cannot continue to do what they do, statutory services must help, thus adding to the pressures on an already stretched system.

"Informal care" just doesn't do justice to the role they undertake – it's just become something that is so much more than living with someone who has needs. The unpaid carer is their absolute 24/7 lifeline and we, as commissioners, rely on them".

4.23 One officer suggested investment in supporting carers is relatively low when one looks at what it can offset e.g., the cost of supporting carers against the cost of providing statutory services. Even a small additional number of people requiring statutory services (domiciliary care or residential) could have a significant financial impact. Furthermore, if carers are not well supported, the circumstances can take a toll on them, and they too may then need care and support.

Action

4.24 Action to uphold carers rights is broad ranging. Initiatives and actions listed earlier helps to identify carers, discuss their needs, and offer support. Other action includes the following examples, which might be found in one or more local authorities:

- A dedicated carers team or a team member e.g., a Carer Champion, a Carer Officer, or a Carer Engagement Officer.
- Contracting out assessments to third sector organisations to tackle the backlog.
- Working with GP clusters as part of a multi-disciplinary approach to consider the carer dimension for people who frequently use primary care services.
- Communications Team active on social media in promoting the role of the carer and helping unpaid carers to self-identify.
- Staff training – induction and refresher training events covers the Act and the needs/rights of carers.
- New carers strategies and action plans, including a Young Carers Charter, co-produced with young carers, which will be promoted in schools.
- A carers' magazine 3 times a year with basic information on carer's rights, assessments, and support. Distributed to GPs, Jobcentres, hospitals, schools, etc.
- Local events with stands typically covering benefits, carers advice, warm hubs information, booklets, give-away products such as radiator foils. Joint working with representatives of relevant organisations e.g., Department for Work and Pensions, Alzheimer's Society.
- Proactive inquiry e.g., When someone presents to the authority in relation to care and support, they or the member of their family who made contact, are automatically asked if they or anyone else provides care to that person. This leads into conversations about their role as a carer (even if they do not recognise themselves as an unpaid carer or are hesitant about engaging with social services), their rights as a carer and what support might be available.

4.25 While the above demonstrates proactivity on the part of local authorities, there are gaps in knowledge e.g., not all authorities are systematically monitoring the extent to which the rights of carers (known to them) are being upheld.

"Making progress but don't know what we don't know. For those carers who are known, it feels as though performance is reasonable. Different matter for those who aren't known or refuse or are fearful to engage".

"Would like to think they (carers' rights) are well upheld but not sure many carers would say we consistently get it right".

4.26 Arrangements for carers' assessments vary. Some local authorities use in-house teams while others contract it out, usually to a third sector organisation with relevant experience and expertise e.g., young people, a mental health charity.

Direct payments

4.27 There was relatively little mention of direct payments to meet carers’ needs, and acknowledgement that more use could be made of them, with more flexible and creative thinking on how they can be used to maintain and improve a carer’s well-being to help them continue in their caring role. One local authority said it has increased its use of direct payments for cared-for people as a direct result of the pandemic because it could not provide care and support. In some cases this had been a temporary change but for others it has continued because of the choice and control it offers to the person who needs the care and support.

Challenges and difficulties

4.28 There is recognition of the need to do more, and to address the difficulties in meeting support needs after the assessment. Some local authorities know they need to do more to reach out to people who are unpaid carers. One said they are undertaking lots of assessments but are not advertising or promoting the support which might be available to an unpaid carer e.g., via GP surgeries, in schools (for young carers). It is felt doing so would almost certainly reveal massive under-provision.

4.29 Difficulties in meeting support needs after the assessment stage were also cited. One local authority said the right to an assessment is met for all children referred to them but staffing issues in their contracted third-sector provider means not all support needs are being met. Another said that once young people are identified, they are mostly able to be supported. However, there are limits on resources and money, which tends to mean delivering the minimum level except where additional grant monies become available.

4.30 Challenges to upholding carers’ rights and meeting their support needs can also stem from the response of the cared-for person e.g., younger people who have mental health issues and who don’t see themselves as being cared-for. While a carer has an assessment in their own right, the cared-for person might not want to disclose certain information, which prevents the assessor having the full picture, or they might not accept care. The latter is illustrated by the example of mum of a young man with mental health needs. The mother saw herself as the young man’s carer, but he did not. She asked for respite but for her to get access to respite, he would need to agree to a respite carer or placement. The situation was not resolved, and the carer’s rights could not be upheld because he refused care and support.

Developments

4.31 Discussions highlighted several aspects of practices which are being questioned or considered for improvement:

- Assessments for the carer and cared-for person sometimes look the same, which suggests social workers are struggling to describe the specific and distinct needs of the carers.
- Changes might be needed to forms on the WCCIS system, but this can take a very long time.
- Assessments for carers and the cared-for person being undertaken by different people to examine needs from a different perspective, and to allow the carer to talk to someone who is independent of meeting the needs of the cared-for person.

- Redeveloping the assessment to make it less "official" and formal (which could be why it has stigma for some people) and more of a conversation. Making it less about judgement of ability and more about the carer themselves.
- Consideration of non-traditional models of respite/sitting services and being more flexible in their offers of support.
- There is some overlap for carers who have rights in accessing both health and social care services. Questions were raised about carers' rights being as recognised by the NHS as they are by local authorities.
- Improving arrangements for the time a child transitions to adulthood at 18, when (if they have capacity) they can make their own choices. It is said not all parents seem to accept this. Better links and more co-ordination needed between Adult Services and Children's Services via a planned approach which starts a year or two before they reach 18.

Are carers' rights being upheld?

4.32 Some interviewees were not able to answer this question. Of those who commented, there were mixed views. Some said they were to a large extent or were going in the right direction. Someone in Children's Services was able to say they were because of the arrangements which are in place when a new young carer is identified.

4.33 Overall, it appears not all carers are having their rights fully upheld. First, delays in undertaking carer's assessments. Second, receiving the support they need after the assessment.

4.34 Undertaking carers' assessments is a common problem, with backlogs and waiting lists in most local authorities. Delays of months were reported in one area. One local authority was able to report improvements which means assessments are done with 48 hours. Assessments are not always done as quickly as the carer, and the local authority, would like. In some cases, too, assessments are not being offered to carers when they should be. The reasons for delays and waiting lists were explained earlier in the report with the pandemic being one factor. However, one interviewee said problems with undertaking carer assessments existed before the pandemic.

4.35 Examples were given of how this is being tackled, which included dealing with cases on a needs and priority basis e.g., risk of hospital admission, risk of carer breakdown. One authority said urgent assessments are always done within 24 hours and never not met. Unfortunately for some carers waiting for an assessment, it can mean they are leap-frogged by someone else with more urgent needs, which can further delay their assessment. Some local authorities reported keeping in touch with people on a waiting list to check on their situation and to identify any change in their circumstances. Another interviewee said that priority cases are always seen within 7 days.

4.36 Some work is being done to reconsider the process for a carer's needs assessment. The work had flagged a perception that an assessment i.e., the statutory assessment, must be done for every carer, thus creating a statutory need. This might be right for some carers but not for all. There was a concern about people being added to waiting lists for a carer's assessment irrespective of their needs, whereas their needs might be relatively simple. This might effectively delay another carer who has greater needs having an assessment. The local authority is seeking to break this "all or nothing" approach and place more importance on a" what matters" conversation at the outset.

Case study:

The Council's Transport Unit was retendering from school transport for taxis and escorts. After listening to parent carers, a condition for drivers and escorts to have training in autism was built into the contract. The parent carers group helped to develop a 2.5-hour training session which was designed and delivered. It raised knowledge of autism, how to communicate, and what to do if challenging behaviour e.g., distraction. Such training is important. When routine changes, which might include a different driver or even a different vehicle, it is challenging for children with autism.

4.37 There can also be delays in providing support e.g., finding an agency for sitting services, which can be even more challenging in rural areas. Meeting the needs of carers of people with severe or complex mental health conditions can also be difficult. Assessment might be relatively straightforward but the support typically available might not meet the carer's specific needs. For example, the mother of a young person with severe mental illness did not want to be separated from the daughter but needed her own, possibly even therapeutic, support with space to talk, to let off steam, and to receive some reassurance and support. Locally, there might be providers of practical support but not for the emotional/ psychological well-being support for carers.

4.38 In some areas, the role of a commissioned third-sector provider was praised for its commitment and proactive approach to meeting carers' needs and helping to ensure their rights are upheld. Their staff will actively seek creative solutions when problems arise e.g., flexibility in deploying their staff, moving groups around with a mixture of in-person and online provision, identifying extra opportunities for carers' groups, and advocating for carers to challenge services and decisions if necessary.

Differences in meeting the needs of young carers and older carers

4.39 It was not possible to form a firm conclusion on any difference in the extent to which the needs of young carers and older carers are being met. There are difficulties and challenges for both groups, including gaps in support available, delays in assessments, and identifying carers or helping individuals to recognise they are a carer. There is a feeling both groups are treated the same but recognition that local authority staff cannot speak for carers, parent carers and young carers, hence the importance of this review engaging with carers directly.

4.40 The unpaid carer is not a homogenous group. Individual circumstances, relationships, and preferences differ, and thus so do their needs. This is prominent for young carers. For example, 5–9-year-olds just want to have fun while 13-14-year-olds just need to chill and talk. Conversations can be polarised about adults caring for their partner and children caring for a parent, whereas children often care for a sibling. One interviewee felt parent carers can often be overlooked or not fully recognised. There can also be difficulties in distinguishing between parenting and caring roles e.g., most parents change nappies until a child is two or sometimes older, but it is not usual for a parent to manage this for a child who is seven or older.

4.41 The profile of carers in some areas is reported to be changing and having an impact e.g., ageing carers, particularly those who now need care and support due to conditions they may have.

4.42 Some local authorities say there is more flexibility in meeting the needs of adult carers because of direct payments, which can make it easier to be flexible about meeting carer's needs, especially since Covid. That said, there is considerable variation in the use of direct payments across Wales. There are also difficulties in getting support e.g., a shortage of personal assistants.

4.43 Local authorities are active in making changes when necessary to meet carers' needs e.g., changing providers after performance reviews, commissioning one provider instead of two resulting in better and more consistent performance. They recognise there is more to do. The transition of a cared-for person or young carer to adult carer on turning 18 can sometimes lead to breakdowns in support and is of concern. Another is ensuring carers are offered their own full assessment and not seen simply as being part of the assessment of the cared-for person.

Areas where performance is falling short

4.44 Local authorities recognise areas where performance is falling short e.g., delays in assessments. Capacity is said to be an issue, with continuing staffing difficulties caused by recruitment and retention problems. This is impacting on meeting timescales for assessments and reassessments, which then delay support for the carer. There is a view that support for carers can be seen as secondary to care and support for individuals who are cared-for.

4.45 The main areas where it is felt performance is falling short or where there are concerns about meeting needs are as follows. Some relate to the cared-for person but have a knock-on effect on the carer.

- Delays in undertaking assessments.
- The availability of targeted support, specifically emotional health/mental health - seen as the most important but something which is done the least.
- Lack of respite provision and for some carers, the need for traditional provision e.g., day centres, sitting service. The need to think beyond traditional provision e.g., more creative use of direct payments, with the carer's preference being most important.
- Gaps in care and support e.g., insufficient provision in the community; provision for those caring for people with mental health needs; more 1:1 support for young carers; bespoke support if possible.
- Better understanding of carer's needs e.g., sitting services, short breaks, range of activities for both carers and cared-for persons. Services often need to be bespoke. The gap is creating a huge strain on carers across all ages.
- The need for more joint working with education e.g., for parents of children with more complex needs.

4.46 The lack of suitable respite care is seen as a common problem for all carers and particularly for young carers. Respite can mean different things for different people. The need to change perspective from the traditional Friday to Sunday-night model was cited by one interviewee but the alternatives are not clear. The use of direct payments as a means of allowing carers to choose the support for respite was rarely mentioned. Where it was, there was acknowledgement that more use, and more creative use, is needed.

4.47 While much is being done with schools and colleagues to identify carers, the need to do more to support them afterwards is illustrated by this example of a lack of co-ordination.

Case study:

A 14-year-old boy who has to take siblings to school every morning is always late to school. He is now refusing to go to school because he says they (the receptionists) comment when he arrives in reception and make him "feel like an alien" for being late. He is already missing half the first lesson due to his caring responsibilities, and now the receptionists' actions are leading to him truanting, becoming more isolated, and getting more behind because he doesn't want to face the receptionist.

Barriers to effective support for carers

4.48 Some of the barriers and difficulties staff are encountering to meeting carers' needs and upholding their rights have been highlighted earlier in the report. In summary, the main barriers seen by the local authority officers interviewed are (in no specific order):

- Lack of awareness and understanding among the public of what support might be available and carers' rights.
- Not everyone recognises they are a carer and wants to be labelled as a "carer", or wishes to engage formally with social services, which for some people has a stigma.
- Entrenched systems and processes and a reluctance to change, which can be at an organisational or team level or an individual social work practitioner e.g., "This is the way it's always been done".
- Budget: in one area carers no longer have a separate budget other than any grant funding which can be secured. Financial resources are always challenging. A lack of budget might not prevent something from being done but it can delay it.
- Staffing: social workers are leaving the profession and recruitment is very difficult. Providers are also encountering recruitment and retention problems.
- Lack of engagement: where the cared-for person and sometimes the carer, does not want to engage and/or receive support, either at all or just when the carer is taking time out for respite when they then need alternative support from someone else. Lack of parental engagement and consent can also be a barrier.
- Lack of suitable provision e.g., respite care; emotional well-being support, and recognition that longer-term, not short-term, support is often needed.
- Challenges of grant funding due to its short-term nature, time taken to approve it, complexities in managing it, and inability to sustain support when funding ends.
- Transport, particularly in rural areas but not limited to them. 60-90 minutes travel time to an in-person support group is a major issue for a carer relying on public transport even if bus times fit the meeting time. Cuts to bus services will have a significant impact.
- Capacity problems in CAMHS for children with complex needs/challenging behaviours.
- Questionable engagement from the NHS in some areas. One interviewee said they had not received a single referral from GP/District Nurses or the hospital discharge team in three years. They occasionally received a referral from a health visitor.
- Lack of awareness among the public and professionals about what it means to be a young carer, the positive support available, how that is presented to a young carer, and

how they can access it. The process sometimes gets distorted by reference to “Children’s Services” when, in reality, they do not need to make a referral.

- Rights and entitlements are not always an integral part of services and pathways. Social workers are rightly focussed on the needs of the individual, but some also need to see the bigger picture and the needs of the carer. Meeting the needs of carers could benefit from more attention, including in training for social workers and front-line staff.

4.49 The lack of support for emotional well-being is a particular problem for children. There can be significant waiting times for CAMHS and school-based counselling, with young carers who need specialist emotional support having to wait for extended periods of time. Even then, support is frequently short-term, limited to a small number of sessions which can mean support is coming to an end just at the point the young person feels ready to open up about their problems.

4.50 Some of the above can also be considered as being “unmet needs”, which was also one of the areas covered in interviews. Other comments offered by interviewees were:

- Potential gap for parent carers e.g., with children who have diagnosed or undiagnosed autism, which places significant extra demands on them in additional to the usual parental roles.

- A regional (commissioned) approach can be very positive e.g., excellent support now for dementia support. Feedback from one local authority said carers revealed how some of them felt really abandoned by services at the beginning while others felt completely overwhelmed with information. Newcomers to a carers forum said the service was completely unrecognisable from what they had heard, and they had found the level of support to be “fantastic”.

----

5. Carers' perspectives – focus groups

5.1 Nine focus groups and meetings were held in-person or via online sessions. The ages and circumstances of participants varied. The groups included young carers and older carers. Individuals being cared-for included adults with disabilities, people with serious and enduring health conditions, elderly parents, disabled children or children with additional learning needs or health conditions including mental health needs. In two cases, younger adults were caring for grandparents and a parent-in-law.

Impact of Covid-19

5.2 Participants shared their experience of the pandemic. While a small number of participants reported some positive impacts e.g., becoming closer to the person being cared-for; easier for disabled people to access online sessions; a child with anxiety about attending school feeling better because schools were closed, and better information available online, the dominant theme was how hard and difficult it had been. The main impacts were:

- Isolation, stress, worry, pressure and burn-out.
- Social life and social activities stopped, which added to isolation.
- Support stopped, with many services cancelled, or withdrawn including specialist services for children, carers groups, domiciliary care, and shopping service (all of which had big impacts).
- Illness of the cared-for person and difficulties in having assessment of needs or needs met, which in turn impacted on the carers.
- Worry about Covid-19 getting into the house and stress about risks.
- Carers had to step in for services and support such as domiciliary care, which created additional pressures.
- Some groups moved online with carers feeling less isolated as a result, although some people, especially those living in rural communities, reported difficulties with broadband connections.
- Carers who were able to undertake paid work before Covid-19 having to give up work because the person they were caring for needed to shield.
- Negative impact on carers' mental health and well-being with no support.
- Substantial anxiety and other impacts on children with severe ADHD and on the autistic spectrum, which had huge impacts on parents and families.
- Relationship problems within families.
- In a small number of cases, bereavement of the persons being cared-for.
- Difficulties in contacting social services.
- Impact of long-Covid on unpaid carers.

5.3 Carers also reported the effect of health services, including ambulances, being unavailable or severely restricted to be able to respond to illness or accidents, some of which affected the prospects of recovery of those affected.

5.4 One participant said the pandemic shows that organisations can prioritise disabled people when they want to. Unfortunately, outside of the pandemic, some have chosen not to. Another felt Covid-19 has been used as an excuse for change. They lost their care throughout the pandemic and feel it has been used as an excuse to take the care away.

Support during the pandemic

5.5 Carers received a variety of support during the pandemic. It included:

- Weekly telephone or online welfare calls and checks, although these tended to be about the cared-for person and not the carer.
- Family support, which was helpful for some (although others had to manage alone).
- Activity packs for children.
- Help with shopping and prescriptions.
- Carers banding together to support each other.

5.6 One person realised because of Covid-19 they were a carer as well as a parent. They sought support and did not have to wait long. The assessment was via a video meeting and the social worker was kind and understanding. The person realised her child had been masking their condition while in school.

Upholding rights

5.7 In more than one group, none of the carers had been given information on their rights under the Act. They described the system as hard to navigate. One was aware of the rights because of his professional role but had no confidence in the system to allow him to access those rights. While one participant praised a Team Around the Family for advice and information, others said fellow parents and third sector organisations are their main sources of information and support and provide better information and support in some cases.

5.8 Some carers had been offered respite care but did not have an assessment, and another said there had been no reassessment of the person being cared for despite their increasing frailty.

"The Act has got it spot on, but it's not implemented at all".

5.9 Of those who did have an assessment, none were aware they had a legal right to it. One participant said she had been reluctant to ask for an assessment in case she was deemed unable to provide effective care, but she was pleased to have gone through the process and is now in the process of receiving support.

5.10 The young adult who had cared for their grandparents had done his own research and established he had a right to be assessed. However, he questioned the value of the assessment because it did not lead to him having the respite care he needed.

5.11 The importance of help being available to everyone when they needed it was emphasised. One carer said: "Too often it's a matter of luck, who you happen to speak to, or where you happen to live". Another said they know the law and their rights but asked what happens to people who do not know their rights.

Assessment

5.12 Eleven or more carers had had an assessment of their needs and as a result, some respite care had been provided. In one case, this was overnight care and in another, it was a befriending service. Two carers described the respite services as "unreliable". One other parent had been offered an assessment but had refused it because she could not see how it would help. Another said it was pointless "more [expletive] forms to fill in and nothing came of it".

5.13 A young carer said social services had made "such a mess" of supporting his mother, he did not believe they would be able to support him. This suggests a lack of confidence in the assessment process and what will come out of it.

5.14 Another carer, a parent, had asked for an assessment four years ago and had been emailed about it. However, she said the Team Around the Family kept putting it off and the assessment did not take place. The only respite she has is when her child is in school. She described a situation where no-one listened. Despite raising her concerns, her child was required to attend mainstream education. The result was they had a catastrophic breakdown. It was impossible to get help from CAMHS or from a third sector service as her daughter's IQ was "above its the threshold for support".

5.15 Team Around the Family was mentioned by a few carers e.g., "the support is making huge difference"; a "lifeline"; "outstanding". Others reported long waits for assessment and for services, and inconsistencies in staffing. Another carer said access to support from other services, such as specialist services and housing was an issue. They said it is a constant battle to get the simplest of things done e.g., getting handrails installed.

5.16 Several carers said they had not had their needs assessed and three participants asked how they could have an assessment. Delays in getting a carer's assessment were also mentioned. No-one appeared to have had a reassessment.

Support post-pandemic

5.17 Carers talked about the strain of caring. They described endless rounds of appointments, having to tell their story again and again, and services not speaking to each other. The pressure of effectively having to "case manage" the support needs of the person they are caring for was described as overwhelming by some. Several carers were receiving support from third sector organisations and groups in the community, including peer support from other carers in similar situations. They spoke highly of them.

5.18 There was praise for a third-sector organisation which had been contracted by a local authority to provide support. Its staff were proactive in helping carers to navigate their way through "the system" and in helping them ensure their needs were met and their rights under the Act upheld. It also provided a wide range of practical information, advance and activities including in-person and online groups and local initiatives such as well-being events for carers.

5.19 Participants highlighted many problems they had encountered. While it is not possible to say whether these problems are representative of carers' experiences across Wales, they are all examples of someone's lived experience, and highlight what some carers encounter:

- Day centres not reopening or reopening with reduced hours; overnight respite not being reinstated since the pandemic.
- Informed that support would be provided but nothing happened.
- Not being offered an assessment or being refused an assessment.
- Getting passed from person to person.
- No named social worker.
- A feeling that being a black carer, they were treated less as a carer.
- Complaints or concerns expressed about support being ignored.
- Unreliable respite support e.g., sitting services does not turn up or does not turn up on time, or lack of access to it e.g., 24 hour/overnight respite.
- Carer having to go to court to get a proper assessment of their mother's needs.

- Inconsistency in the practice of individual social workers, with praise for some and their kind, caring, attitude but others being "rude", "dismissive", and "unprofessional".
- Having to start the process of asking for support from scratch when problems occur or circumstances change.
- Having to 'fight' or "battle" for support
- Being put "into a box" and the local authority refusing to think more broadly.
- Took a long time to get respite but ended when turned 18, and still has to care for someone.
- Respite provided but not for a 24-hour period.

Case studies:

A carer whose husband has a progressive condition said there are more barriers now since Covid. Not all services are up and running again. They still do not have a named social worker. If they encounter another problem, they cannot go to a named individual. They must go through the Council's "portal" again which takes time. They must wait for a social worker to get in touch. Then are allocated to another person never seen before. There is a lack of continuity of care. The carer was told no to a referral for a carer's assessment.

An older carer had contacted social services due to a change in the circumstances of the person she was caring for. She asked to speak to her social worker. She was told she no longer had a social worker, and that after initial assessments and services had been put in place, the person she was caring for had been discharged. They had to go through another full assessment process to get support for her partner's changed needs.

One carer reported real issues with a third sector organisation which was supposed to provide respite care and the paid carers who came into the home to support physical care. The organisations failed to communicate with each other, meaning it was very difficult indeed for her to plan to be able go out. She sometimes had paid carers and respite support staff turning up at the same time, sometimes not at all, and never in a reliable pattern.

5.20 In some areas, day centre provision has been replaced by befriending services where individuals - paid carers or volunteers - visit the cared-for person at home, supporting recreational activities there. While carers welcome any support, they say it does not provide the same respite as the day care centres. It is not always reliable and therefore difficult for carers to plan to go out, and it does not provide the social interaction the two individuals being cared-for had enjoyed.

5.21 One carer said their local authority area has consulted on changes to support provision for adults with care needs. They appreciate budgets are tight, but it appears there will be half the provision there was before Covid. They question what a carer does in a few hours, particularly in a rural area when travel takes so long.

5.22 Some groups are now back face-to-face but some carers still meet online. It works for some people but is not the right solution for everyone.

Case study:

The need for "lower level" support to improve the quality of life of carers was mentioned. One carer had a shopping and cleaning service so could use their respite time to see friends and family and to relax. Now, without such a service, they must use their respite time to do shopping. Online shopping is no good for them as there is no broadband where they live. The result is that they do not see anyone anymore.

5.23 The support being received by carers varied according to circumstances and needs. Providers included Team Around the Family for after-school activities and overnight respite care, and support from a personal assistant provided by the local authority to an individual to participate in activities and to help with learning life skills. However, a carer said the latter has proved somewhat unreliable and therefore the family are pursuing the use of direct payments to give them more control.

Case study:

Following the experience of Covid-19, a parents' teenager has become too anxious to go to school. The parent was not receiving any respite support. However, this was not due to a refusal by social services to provide it but due to a difficulty in recruiting a PA with sufficient skills to be able to meet the young person's needs. The parent described the support that she has received from the Team Around the Family as "Outstanding", praising it for organising everything for her, including making sure the parent gets him to appointments. She said it has taken a long time, but now they are getting some help and it is making such a difference.

5.24 Some parents were receiving no support. One parent was paying for an after-school club once a week and a breakfast club for her disabled child to enable them to spend time with her other children. Another family was paying for a residential special education placement which met the needs of their child, but this is unsustainable.

5.25 Parent carers said specialist services such as speech and language, dietician, and consultant paediatric services, were withdrawn during the pandemic. They said they have not been restored either because of long waiting lists or because thresholds for receiving care have been raised. While these points relate to health services, they are mentioned here given their impact on carers.

Case study:

One carer had been offered and had received counselling support, and this had made a huge positive difference to her. She would like to be able to access this again but has been told that this is unlikely as the person she is caring for is "no longer in crisis".

5.26 The impact on carer's working lives was also mentioned. A few carers asked for flexible support now or at some point in the future which would enable them to return to work as it would be hugely beneficial, not only financially but for their own well-being.

Respite

5.27 Much of the feedback from carers referred to care and support for those they were caring for and not about themselves, which highlights their tendency to focus on those they care for.

5.28 Several carers said they find it difficult to differentiate between services specifically to support them as carers and services for the care and support of the people they are caring for. Some services have a dual role of care and support to meet an individual's needs while at the same time supporting the carer, usually by way of respite from their role.

5.29 Of all subjects covered during discussions, respite was mentioned most frequently and is clearly one of the main ways of helping an unpaid carer to cope and to continue the key role they undertake. There is a lack of respite provision or a lack of suitable respite provision i.e. provision which meets the needs and/or preferences of the carer. One carer said that after asking for respite, all that was offered was time in a care home, which they did not want. According to carers, respite is misunderstood. For a carer it could be something as simple as a membership to a book club; something which allows the carer to relax. One mentioned an approach which focused on giving some time back to the carer as an individual.

5.30 Coordination of care and respite support can also be a problem. One carer said an independent provider provides care three times a day. After a carer's assessment, they have had some support sessions with a third sector provider. However, there is no communication between the two sets of providers to co-ordinate the provision and as a result, the carer is unable to change times of one set of provision to get full respite from the other provider.

What more could be done for carers?

5.31 Carers were asked what more would help to support them to continue their role. While the discussion was about them as carers, issues relating to the person they cared for were prominent, which perhaps reinforces the notion that unpaid carers put the needs of the cared-for person ahead of their own.

5.32 For the cared-for person:

- Effective, adequate, reliable services.
- Restoration of day centres which were available before the pandemic as replacement services such as befriending do not necessarily do the same job.
- Consistency with staffing to overcome the difficulties a cared-for person has with constant changes of paid carer.
- A named social worker.
- Easier access to accurate assessments of a child's needs, reduced waiting times and more flexibility in specialist services such as speech and language therapy.
- Better co-operation and co-ordination between departments and services to meet the range of needs, and better access to specialist services when needed.

5.33 For the unpaid carer:

- Reinstatement of services which have not reopened after the pandemic, or which have reopened with less hours or with different (higher) thresholds for support.
- Help with effective case management; the sort of role that might have been fulfilled by a social worker in the past.

- Someone to help them manage the support needs of the person for whom they were caring and to navigate the system.
- Access to consistent, high quality respite care (cited as a major need).
- Support for their own emotional health and well-being mental health needs, including counselling, and for any personal health needs.
- Better co-ordination and joint working between organisations so carers do not have to tell the same story time and time again.
- Better information on all the rights of unpaid carers and all the support available, and information which is easy to find on local authority web sites.
- Front-line staff e.g., first point of contact, need to understand law and carer's rights.
- More personal assistants and better training so there are more opportunities for respite for people caring for children with complex needs.
- More use of direct payments and more flexible / creative use of direct payments e.g., to allow a carer to take up a hobby or cleaning help around the house, all of which can help a carer to cope; some local authorities restrict how direct payments can be used.

5.34 A young carer said they hoped they could have a support worker again who could take them out and spend time with them in addition to the out-of-school group. The support stopped when there was a change of provider.

5.35 In addition to the above, feedback from carers also included criticism and suggestions. Many reflected individuals' personal experience but there were also some common themes. The following are the main points (in no specific order).

Language

5.36 Four participants and the people they care for were fluent Welsh speakers. Two of those being cared for have dementia which can mean they may experience the loss of their acquired language, which is English. None had been offered services or assessments through the medium of Welsh and none were aware they had the right to request services through the medium of Welsh. Some of the assessments and/or services had been conducted in Welsh, but this was described as purely as a "matter of luck".

Transition to adulthood

5.37 The transition from Children's Services to Adult Services when their child turns 18 is a major concern for parents. It was described as a "cliff edge" and "like trying to navigate through a minefield" and "bureaucratic". A parent reported being terrified of saying the wrong thing and having their child's services withdrawn. All parent carers with children older than 11 described the huge negative impact on their mental health and well-being because of worrying about this issue.

Çross-border issues

5.38 Several parent carers also reported difficulties with cross-border issues e.g., if a child is educated in England but lives in Wales or vice-versa. They reported having received incorrect advice because staff did not understand the different service provision, law, and regulations in the two jurisdictions.

5.39 While the above example relates to the England–Wales border, similar problems can arise across local authority areas within Wales. One parent highlighted a broad problem. They live on the edge of a local authority's area. For her child, social care is based on where she lives i.e., postal address. For the NHS, it is based on her GP which is in another local authority area. As a health service, CAHMS is based on where she lives and who is responsible for her social care. Education is where she goes to school.

5.40 The above suggests the lack of coherent approach. Parents said they feel some organisations are "passing the buck", with budget reasons being one possible reason. They reported often having to start processes all over again when referrals are made between organisations. This echoes other comments about having to tell their story time and time again. The need for more joined-up, co-ordinated, services was emphasised.

Stigma

5.41 Stigma and discrimination against children and young people being cared for is a significant issue for some carers e.g., children and young people with invisible disabilities such as autism. They described a lack of specialist age-appropriate services, particularly for young adults. Parents of children whose conditions made them display challenging behaviours described discrimination within services which are supposed to help them care, and a constant fear of the child being taken into care because of being perceived as a "bad parent'" rather than a parent struggling to manage the behaviour of a child without an accurate diagnosis. They also suggested training for workers in universal services e.g., transport; leisure, to reduce stigma.

5.42 A young carer said he received support in school and from a third sector provider outside school. Both are important but the understanding of the school particularly so as sometimes they miss school or are late. They have received a young carers allowance which has been helpful to buy some treats and some new clothes. They praised the Young Carers ID card but also said they do not want too many people, particularly in school, to know that he is a young carer. They are worried that while most people would be nice about it, he is concerned they might not if they knew their mother had mental health problems because of the stress of looking after their disabled relative.

Money

5.43 The financial cost of caring and economic pressures is a significant issue for most carers. Three had had to give up paid employment to care and their standard of living had been severely impacted. They talked about the complexity and inflexibility of the benefits system. The stigma attached to relying on benefits was a particular issue for carers of working age. Some also felt care packages were offered to them based on cost, rather than on what is needed.

General themes

5.44 Over and above the subjects covered, several other issues emerged from discussions:

- Inconsistencies in approach at the organisational level and individual social worker levels. Much depends on where someone lives and which social worker someone has. Some social workers are very good and understanding and caring, while others are not.
- Carers feel staff working from home is probably having an impact. Some council offices are not used so a carer cannot call in to talk with someone.

- Some assessments are being done by social workers living in another area (probably agency staff brought in to help clear a backlog). The social worker in Cardiff says they cannot come out to mid Wales to visit so the assessment is done remotely.
- Sometimes, things must reach crisis point before anything happens.
- Carers not being informed about funding to which they are, or might be, entitled.
- Very difficult to know how to get help and who to contact at the start and when things change or get worse.

----

6. Carers’ perspectives – online survey

6.1 An online survey was developed in response to difficulties carers had in attending in-person or online groups due to caring responsibilities. The survey questions are in Appendix 1.The survey was publicised in the seven local authority areas in the review. Emails were sent to carer networks and to third sector organisations and groups. Social media was also used to raise awareness among carers. Responses were received from 302 unpaid carers. Three respondents used the Welsh language version. It is possible some carers who responded to the survey live in areas other than those of the seven local authorities in the review.

Table 1: Age breakdown of survey respondents, unpaid carers, 2023

Age group	No.
Under 18	27
Between 18-25	7
More than 25 years of age	268
Total	302

6.2 The survey sample was self-selecting and therefore, cannot be confirmed as being representative of unpaid carers. Some caution is also noted on its reliability i.e. if the survey was repeated, would it produce the same results. That said, it reflects the lived experiences of a substantial number of unpaid carers and is a valid measure in relation to the objectives of the review. Some respondents have already engaged with social services while others have not and will not be known to social services, which is also important to understanding the extent to which the needs of unpaid carers are being met and their rights upheld. The survey did not ask about the impact of Covid-19; this was covered in the focus groups. However, many comments referred to related matters e.g., health and well-being, anxiety and isolation, the impact of day centres not reopening, and changes in support.

Overview

6.3 Feedback from carers included general comments and comments on specific subjects. The general comments comprised positive and negative elements.

Diagram 1: Examples of positive comments from carers

Thank you.

It’s rewarding

Tiring but very worthwhile.

Very happy with support I'm getting.

Excellent support from social services.

Caring is a duty and occasional privilege.

Wales more proactive than England were.

Council’s help and support has been so valuable to me.

Grateful for the support I receive.

Experience as a carer has been good.

Spoke to a lovely lady who directed me to support.

Got help quickly.

I am so grateful.

6.4 Several carers commented positively about the role of third sector organisations, and the information and support they have provided. Some of the organisations have been commissioned by councils for this purpose. A young carer said they like they have somewhere to go where they are made to feel special, and they have also learned some great skills to help them at home.

Diagram 2: Examples of negative comments from carers

Nothing happens until it gets difficult.
Feel undervalued.
If nothing goes wrong, no one cares.
Such a hard job. Never felt more alone.
All we get is "we'll look into it".
I hate it, loss of choice, lost independence, soul destroying.
Services available are woefully inadequate.
We're overlooked and nobody listens.
Unappreciated, exhausted, and flagging.
Feel abandoned.
I am 83 and exhausted. Must carry on if support not forthcoming.
Empty promises.
Not getting any support.
We are invisible.

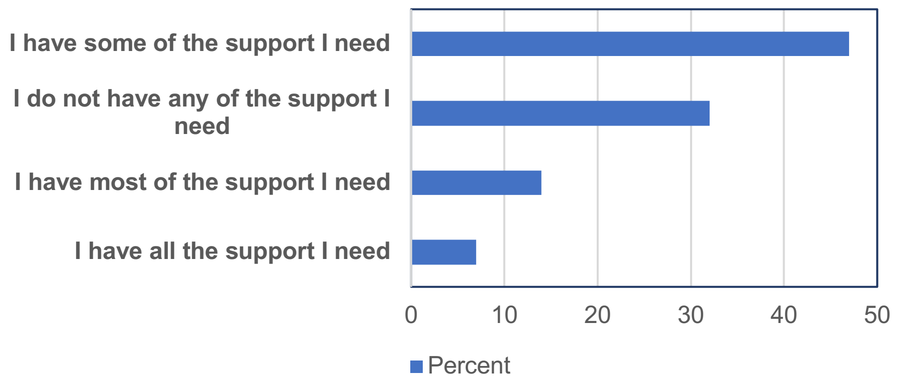
6.5 Carers living in rural areas highlighted the additional problems they face in being able to have support or take part in support activities due to the distances and transport problems.

6.6 The following pages reflect carers' comments on specific themes. Inevitably, many are interconnected and/or interdependent.

Meeting the needs of carers

6.7 In the sample of carers, there appears to be a significant deficit in meeting needs. Fewer than 1 in every 10 carers (7%) said they have all the support they need and 14% have most of the support they need. Just under half (47%) said they have some of the support they need. One in every 3 carers (32%) said they do not have any of the support they need.

Chart 1: Extent to which unpaid carers have support they need, May 2023 (n=302)



6.8 For carers under 18 years of age, 33% had all the support they need and a further 33% had most of the support needed. 27% had some of the support and 7% said they had none. The small sample size (n=27) should be noted.

6.9 Irrespective of the caveats on the survey sample in paragraph 5.3 above, and as shown in the chart on the previous page, the results suggest the needs of many carers are not being met. Approximately 1 in 5 carers (21%) have all or most of the support they need. The other 4 out of 5 have some support or none at all.

6.10 The apparent deficit in meeting needs does not necessarily mean all local authorities are failing in their task. For reasons explained in the previous chapter and feedback covered later in this chapter, not all carers have engaged with social services. However, it does raise questions about the extent to which unpaid carers are being informed of their rights and reached with proactive offers of support, how requests from carers are handled, the extent to which their needs are assessed promptly, and how needs are met after assessment. Two carers said they were told a lack of funding prevented their needs being met.

6.11 Three respondents said they had noticed a significant differences between local authorities when moving from one area to another.

> *“We used to live in [- area-] where the services at the [-centre-] were fantastic, there’s so many things that can be accessed via the facility. In [-area-], the only way we’ve managed to access specialist sessions for kids with disabilities places or get support is by approaching companies directly like [-examples-]. We’ve had such a lack of support that my husband has left a well-paid job and dropped down to a 3 day a week minimum wage job to be able to help in the holidays and so he has some time for his own mental health without our son home. We now receive Universal Credit, and he doesn’t earn enough to pay tax. I feel we’re now very reliant on benefits and have had to make this call all because of the lack of support we’ve received. To summarise the support we’ve received from [-local authority-], it has been shockingly minimal and very slow to arrive”.*

6.12 The survey asked carers what more could be done to support them which would improve your well-being? Common themes were (in no specific order):

- More information on support for carers and how to access it, and their rights. Proactive distribution of information to reach out to carers.
- Better web sites and information e.g., no “jargon”
- Simpler paperwork and less forms.
- Greater recognition of unpaid carers, with more value placed on the role.
- Ability to get a carer’s assessment without delays or waiting lists.
- Being able to get help and support, particularly after it has been agreed.
- Keeping to promises e.g., responding to calls, providing support.
- Respect and understand from professionals and not being judged.
- More consistent approaches by social workers; some are kind and understanding; others are dismissive.
- Fewer changes of social workers.
- Not having to “fight” for help.
- Not being passed to and fro between organisations or departments.
- Not having to repeat their story time and time again.
- Work with carers to determine support as they know their circumstances.
- Give carers opportunities to train others and get them to work together.

- More respite care e.g., day services; overnight respite care; respite for breaks and holidays, support groups, and to enable someone to work.
- More support, including 1:1 support, counselling; someone to talk to, and more support and activities for children with disabilities in the holidays.
- More reliable support as some providers have missed visits.
- Financial help, including an increase in the carers allowance.
- More personal assistants.
- More support for carers in workplaces.
- Better arrangements when a cared-for person turns 18 and moves from children's services to adult services, and for young carers when they become adult carers.
- Better co-ordination across departments in local authorities and with other services such as health services.

6.13 Several carers cited difficulties in finding information about support or getting support and having to "jump through hoops". Some respondents believe these hurdles and thresholds for support are designed to limit demand. One described them as barriers rather than gates at the point of access. Parents with a child with disabilities or an autistic child, sometimes with mental health problems, reported difficulties in getting support and financial support.

"Be aware or informed of any correspondence/communication to the person being cared for, especially where the cared for person has a cognitive impairment. An example is where, because of a day service referral, a few phone calls were made to a deaf person who was unable to respond. This was followed up by a letter informing that the referral would be closed unless there was a response. This letter was only found when clearing out the property of the person referred - filed in a photo album. No day service was ever received despite follow-up enquiries".

"There is a complete lack of real alternatives to so called respite care, we would never dream of sending our daughter to the places available in our area. As we have literally never been offered anything in nearly 40 years, we are sceptical that anything will ever be offered. Meanwhile, just down the road people we know are foster parents are getting paid a lot having regular breaks and more, doesn't really seem that fair to unpaid carers".

6.14 One carer, a black single parent, emphasised the right to be spoken to with respect, processed according to the law, and given the same opportunity to thrive as any other citizen without harassment or victimisation.

6.15 Better health services were mentioned by several respondents, and a call for more co-ordinated working with social care. While on the edge of this study, comments are reported where it is relevant to, or has a direct impact on, carers and their ability to provide care.

6.16 The following pages expand on the main issues raised by unpaid carers. Examples of quotes are provided; these reflect the lived experiences of unpaid carers.

Recognising and valuing unpaid carers

6.17 Some carers were vociferous about the lack of recognition for what they do, seen as "free labour" and the "cheapest social care you can get". They feel help should be offered not left to a carer to find out themselves. They say no-one, including government, cares about the carers, with "lip service" paid to their needs. One said the title "unpaid carer' is humiliating.

> *"Being an unpaid carer feels like you're a slave to the system. I would always look after my husband to the best of my health abilities, but it has taken its toll on my health now and the authorities do not care, and turn a blind eye, if it wasn't for unpaid carers the system would be in chaos".*

6.18 It is fair to say some carers are sceptical about whether anything will change because of this review, citing previous surveys and consultations which have not made a difference. A small number of carers said they lacked faith in government as the Act has had no effect for them. Another doubted the investment being made in social care.

Carers' rights

6.19 In the sample of 302 carers, there is relatively little awareness of carers' rights in the Social Services and Well-being (Wales) Act 2014. One in 4 (25%) said they are aware of their rights. Nearly half (45%) said they did not know their rights while the remaining 30% were unsure or did not know. This suggests most people do not know they might be able to challenge local authorities if an assessment is not offered or if support is not forthcoming.

6.20 One respondent said the legislative framework is there but is not followed or enforced. Another said rights mean nothing when councils are aware someone cannot enforce them without a solicitor, which most people cannot afford. Carers report having to "fight" for their rights. Several parents of disabled children said the legislation should enable them, disabled children, and their families to have the support they need, including respite care and short breaks. Most comments on legal action were in an educational context e.g., special educational need.

6.21 A small number of carers expressed concerns about dealing with social services. They said they are afraid the person they care for will be taken away if they made a fuss or question professionals.

Assessment

6.22 There are two main issues. First, an inability of some unpaid carers to have an assessment or a delay in having it. Second, as highlighted earlier, even if support is granted, some carers report none is provided. Some say support is forthcoming when a crisis occurs.

6.23 There were numerous reports of assessments not being done e.g., assessment requested 3 years ago and only partially completed, or delays of several months or up to a year. One carer said they had been refused a carer's assessment because although their children are disabled, their IQs are "higher than the threshold for support".

6.24 Carers ask for more frequent re-assessment as needs can change relatively quickly, although most seemed to be commenting about reassessment of the cared-for person. One carer said they have not had a reassessment for 18 months. Another said they have had one assessment in 5 years, leading them to think they are being taken for granted. Even if not a reassessment, a carer said it would be nice to have someone ring from time to time.

6.25 One carer commented on the resources available to support carers. They said there was no point in having an assessment when one is then told *"we do not have a budget so can only signpost"*. Many carers already know about third sector groups but need something more.

> *"I requested a carers assessment in November 2022. I have had a pre-assessment but still no assessment 6 months later. I have no idea if I will receive any services from my carer's assessment and no idea when it will be completed. Actually completing an assessment would help me. I cannot say anymore as I do not know what I will qualify for in the way of my well-being".*
>
> *"I had to push very hard to get [-council-] do a carers assessment for me even though it's my statutory right. The outcome of this was that I "have some unmet needs" but [-council-] did not offer to support me to meet these in any form. I care for two adolescent disabled children, have no leisure time for me, can't attend church and would really like to learn Welsh but can't get regular childcare to attend lessons".*
>
> *"I've been waiting for a carer's assessment in [-council area-] for months. I am very stressed. I have health complications of my own as a result of being an unpaid carer".*

Respite

6.26 Respite care, or the lack of it to be more precise, was one of the subjects mentioned most frequently. Many carers do not have family or friends to support them. Many are clearly struggling without adequate respite, which can be stressful, isolating, and exhausting emotionally and mentally. Many have lost social contact with friends as a result. All this places them under even greater pressure. This impacts their health and well-being, which risks a crisis and a carer who is no longer being able to cope. In such circumstances, statutory services would have to step in adding to the demand on an already stretched system.

> *"Respite is key. Sometimes I feel like I'm living a prison sentence because I have no freedom. My child has been unable to attend school and is waiting a specialist placement and am corresponding with all different organisations. It's very difficult to get uninterrupted time to focus on life admin, especially those that involve my daughters care. My husband is now medically retired, and his memory is deteriorating so I can't rely on him and have to take in everything. People offer you courses and therapy, but I have no time from caring responsibilities to do this. I have had to give up my job recently because I cannot cope with it all so now I'm even more isolated".*

6.27 The lack of day services or overnight respite were mentioned many times. This appears to stem from day centres not opening after the pandemic or opening with reduced hours, or being replaced with other forms of respite, such as sitting services. Some carers said one size support does not fit all; needs can be complex and generic support is not suitable.

6.28 Some carers simply asked for their role to be recognised with a break or holiday when they need it or even a few hours respite so they could have some time to themselves or see friends or help around the house such as cleaning which would reduce the pressure on them. This in turn would help address exhaustion and benefit their own health and well-being. Developments such as the Carer's Card which allows access to leisure centres are welcomed but as one carer pointed out, it cannot be used if respite care is not available to allow it to happen.

6.29 Accessing respite has been very difficult for some people. For example, parents who said a year into the process still do not have any support in holidays or at weekends. The father has dropped his work hours to help manage and the couple is now in receipt of Universal Credit. One carer said it is better now that they are on the system but asked why it took two years. Another said it should not take months on a waiting list to get a social worker, then respite taking more months to organise. Several carers reported being awarded respite support e.g., 6 hours a week, and then having to wait months to get it.

"Make sure respite care is actually available. I have a grant to pay for care. But no agencies have dates available. I have not had a respite day for three years".

"I appreciate there is a lack of PA'S so the 15 hours awarded more than 3 years ago have not been filled at all. I am now a pensioner and struggling with medical appointments, chores etc in the meantime the one I care for and I are more isolated. Maybe someone to take us for a drive and a coffee or day out would be nice. Even a shopper.

"I need respite as I care for two. I desperately need carers to come in and help with my son as he is violent, and I can no longer keep him safe".

"My son is entitled to 4 hours respite term time 8 in holidays. He has had nothing since October".

"A respite service, I'm a single mum of 2 children with autism with no support and its exhausting to the point its now physically effecting my health".

"More hours via direct payments are desperately needed and we cannot employ a second PA so we still have to go everywhere with our daughter and her single PA because she requires 2:1 care. Therefore, no respite at all".

"Respite care would help. I've been caring for my wife for over 17 years now and haven't had a break".

"No respite care, no care outside of school hours so I can work, limited opportunity for my son to socialize without my support".

6.30 Where some respite has been provided, some carers say it is insufficient. For example, someone given 1 hour when it takes that long to get into the local town on the bus. Carers refer to the changing needs of the person(s) they care for and difficulties in having reassessments, sometimes having to start the application process from scratch all over again.

6.31 One parent carer said they can never have the respite to take a holiday themselves or take their other children on holiday. When behaviour is so challenging it is hard to leave the house, so siblings never experience a holiday. Another said they just need help with caring for their mum so they can have a break, saying that in 10 years, they have had only 4 weeks and a few weekends away, and that was only in the last eighteen months.

"The social services do not understand the pressure involved on an unpaid carer. My husband is registered housebound, I have to get up in the night sometimes when he is in pain and give him some pills. They say my 15 hours a week is too much and intend to cut it in the near future. When the carer is here, I have to rest. I have not had a day off or a holiday for five and a half years. I don't like being spoken to like I'm asking too much, like I'm a pain".

> *"I receive no help to carry out my carrying responsibilities. It is exhausting and it is affecting my own health negatively. This will cost the NHS more to care for me in the long run. I care for 2 people who need 24hr care but who have entirely different needs. Services that meet their individual needs would help me and them. It's tough. Working full time and caring full time".*

6.32 On a broad note, there is a call for the government and local authorities to acknowledge that without an unpaid carer, the cared-for person would be at high risk of neglect and harm. Respondents asked for respect, recognition that some unpaid carers have abandoned well-paid jobs and fulfilling careers to provide care, and an end to closures of services for adults with learning disabilities. They asked to be seen as "experts" and to stop assumptions that "one size fits all" care packages which assume carers need a few days off a year.

6.33 The lack of awareness of carers' rights is compounded by a lack of awareness of support which might be available, and for some people, difficulties in finding it.

> *"I struggled for many months as a carer as I wasn't aware at all of any of the support that was available. I contacted one charity who brushed me aside with an answer that they didn't have the resources and therefore "it's just you I'm afraid". I was totally unaware that I could obtain help and support from Social Services for an elderly parent".*
>
> *"I haven't registered with any organisation. I am a 66-year-old single woman. I have given 24/7 care to my 91-year-old mother for the past 6 years. She lives with various health issues including Vascular Dementia. Our surgery is aware but not proactive. Perhaps they should be the first point of call for offering any assistance. The help I do have is from my aunt who has my mother occasionally thus giving me some respite. I organised a stair lift. And now a wheelchair. Have started a blue badge application several times but not completed it. Life is difficult enough to navigate without the hurdles involved, in what should be an easy process".*

Young carers

6.34 The main calls from carers aged under 18 were:

- Counselling and 1:1 support.
- More help for the person they care for.
- More staff being available to help them as young carers.
- To be treated as individuals.
- More activities: the ability to socialise.

6.35 One young carer asked for more contact. Not everyone wants to just receive emails that are about day trips, cooking, cinema. It is more about welfare of the young carer and how they cope day-to-day with looking after a family member. More frequent house visits to sit with the carer and the family member and ask them how they are doing.

> *"It's sometimes hard to attend regularly to school and sometimes is embarrassing to explain to people the absence reason e.g., my dad with dementia was screaming all night and I couldn't sleep".*
>
> *"It is not fair that my life is affected by my sister that keeps screaming all night and I can't focus on my studies, neither it's my fault to be in this situation".*

Direct payments

6.36 The use of direct payments to give carers choice and control was mentioned several times although largely in the context of care and support for the cared-for person. The shortage of personal assistants was highlighted, with calls to help finding them and for the responsibility of these vital workers to be recognised by paying them more and professionalising the role. A couple of carers said they have had to return payments because they cannot find a personal assistant.

6.37 Several comments referred to the sort of support which can be obtained using direct payments e.g., respite care to allow breaks; practical assistance such as shopping or cleaning to free up some time to relax and for leisure, which can help well-being and reduce stress. This type of support is possible if the local authority has a flexible and creative approach which focuses on achieving the well-being outcomes for the carer. Not all do. In some parts of Wales, local authorities restrict how direct payments can be used. One carer said if they could have driving lessons, they could help the person she cared for and would also not be as isolated as they now are.

Healthcare and health services

6.38 Respondents highlighted aspects of health services which impact on them as unpaid carers. For example, a lack of understanding by GP surgeries of the role carers play, with "obstacles" in the way of them accessing healthcare for the cared-for person. Also, access to health services at more convenient times with a booking priority for not only the cared-for person but the unpaid carer. One suggested GPs putting a marker on patient records, so they are aware of carers. According to local authorities, this does happen in some practices.

6.39 Unpaid carers can encounter difficulties in getting medical advice. Carers health tends to come second. One respondent asked for support to enable her to attend her own medical appointments.

6.40 The need for more co-ordination and communication between health and social care services was mentioned by several respondents. One referred to a daily struggle to establish who should pay for, or provide, support. They said the lack of appropriately trained staff to undertake Continuing Health Care assessments in the home is "diabolical". They said no-one will take responsibility; each discipline expects someone else who do it. GP, nurse, and social workers all pass the buck and won't undertake them, so patients are left without the assessment and funds for their care are then blocked.

6.41 One carer described difficulties she has had in trying to find support for her son while undergoing chemotherapy for breast cancer due to the lack of overnight respite. While she has a care package for him, some hours are missing due to a lack of staff, which she covers. She emphasised the need for emergency cover; if her temperature exceeds a point, she must go straight to hospital, yet she cannot get to hospital if there are no carers available.

> *"Childcare respite. We have been allocated a 30-hour nursing package but get zero hours due to not having enough nurses (can't be HCSWs). We don't want residential respite but a safe place where he could go and have fun and staff are trained would allow us to have some downtime and also time to have the important conversations about how we are coping and what the future holds."*
>
> *"Emotional support is aimed at young carers, older people, or parents with learning difficulties/ASD. There's very little support for families and parents or children with complex medical needs. It can be very lonely. The only emotional support outside of the hospital has been [-third sector organisation-], which offers an online catch-up every couple of months."*
>
> *"Regular visits from a district nurse or GP to take the pressure of diagnosis and monitoring off me. My 93-year-old father has had 2 GP visits since leaving hospital 4 years ago. The GP even gave me two courses of antibiotics and told me to decide if and when Dad needed them so that I couldn't have to bother him."*
>
> *"I also need to get some sleep at night as my wife needs help getting to the loo and needs help getting back into bed. I'm having difficulty understanding her as her speech is affected by the illness and I have a hearing problem and wear hearing aids. But even with the aids I find it difficult to understand what she says".*
>
> *"Extra hours sitting service and respite because I only have 6 allocated hours for sitting service and have been told that it would be difficult for respite because my husband is seen as nursing care so puts a lot of pressure and stress on myself and husband".*

Financial matters

6.42 Some carers explained they have been forced to give up their jobs, well-paid carer jobs in some cases, to provide care. This includes parent carers and, for example, adults caring for elderly parents. It creates financial pressures for households, some of which are significant. Others are continuing to cope by combining work with caring but say due to earnings they are excluded from receiving certain benefits and allowances despite the extra costs of providing care. The carer's allowance or DLA for example, do not necessarily cover all the costs e.g., it falls well short of the actual cost of the continence products which are needed day to day or heating costs, both of which have increased. Parent carers also report having to take unpaid leave to care for their child during the day and exhaustion due to lack of sleep due to the care needed at night.

> *"Respite care needed and an increase in carers allowance to reflect cost of living crisis, increase in number of free nappies/incontinence pants given (only given 4 a day, whereby get through 10 - 15 a day, and cost of nappies have risen by £30 a box). More provision during school holidays and free provision as £15 pounds a day is very steep in today's financial climate".*

6.43 Other carers are seeking care and support as they would like to be able to work, and in some cases need to for financial reasons. Some carers have spent their savings.

6.44 One person suggested child carers should have money put into a trust fund so they may access it when they are older to help with driving lessons, training courses etc. They feel the fact they are not paid anything is disgraceful.

6.45 Several carers called for the allowances such as the carer's allowance to be increased or for carers and parent carers to be paid a wage, without it affecting the allowances received by the person being cared-for. They highlighted the role they play in saving money for the Government which would need to provide the service and support if they could not do, or did not want to do, their role as a carer.

Workplace support

6.46 Several carers called for more support from employers, action which the interviews with local authority staff indicates is happening in some areas. The need for workforce policies to distinguish between someone offering intermittent care and full-time care was highlighted. Carers indicate a desire to keep working but it is not easy and, as reported elsewhere in the chapter, some carers have had to give up work which has created financial pressures.

Personal and family difficulties

6.47 A small number of carers cited personal and family difficulties which affect them and the impact of their role. These included, for example, parents who refuse to accept any care and support from social services or from agencies working on their behalf. For others, it is a lack of support from other family members e.g., siblings, who are not prepared to share the caring responsibilities.

6.48 One carer explained a difficult situation. The person they care for, who has mental capacity, refuses care and therapy but is abusive to the carer. The carer feels alone and there is no help. They were told it is the person's free will to engage with services but do not feel they should suffer as a result.

----

7. Findings

7.1 This review generated considerable insight into the work of local authorities to support unpaid carers and the lives of unpaid carers and the challenges they face. The authors are grateful to everyone – local authority staff, staff in the third sector, and carers – for sharing their views. Carers' views reveal the immense pressure they are under, the impact on their own health and well-being, and their experience in seeking help. Inevitably, there are good experiences and poor experiences, with feedback tending to focus on the latter.

7.2 Having examined the subjects of the review from all different perspectives, this chapter summarises the main findings.

Impact of Covid-19

7.3 There is consensus on the significant impact of Covid-19 on unpaid carers, with greater reliance on them for care and, despite considerable action by local authorities, an extra burden. Carers with protected characteristics were sometimes affected to an even greater extent. Some of the impact was directly on carers while other impacts stemmed from the impact on those they cared-for. Either way, the impacts are many and varied, both physical and emotional / mental health and well-being.

7.4 For many carers, there is a legacy of impact. This can be from health issues, including a deterioration in the condition of the person they care for or their own health, or continuing anxiety about Covid-19. Others impacts stem from support not reopening in some areas e.g., day centres, or support being reduced e.g., number of hours or being replaced with alternatives forms of support.

7.5 There are some positives. The pandemic challenged many traditional ways of working, particularly in communicating with carers and young carers. It caused local authorities to think differently and "out of the box". There was a rapid transformation of working practices to deliver alternative forms of care and support and at points, more frequent contact through weekly welfare checks. Some developments, such as online groups, also enabled more people to participate e.g., people with physical disabilities.

There is broad agreement on the significant impact of Covid-19 on unpaid carers and the extra burden placed upon them. The pandemic improved some ways of working, and many have continued, but many carers are affected by services not reopening, opening with reduced hours, or changes to the services now available.

Financial impact

7.6 The more recent issue of the increasing costs of living has risen to the surface and for many carers has eclipsed matters relating to Covid-19. Many carers including parent carers, and some who have had to give up well-paid jobs because of their caring role, reported significant financial pressures. This emphasises allowances and benefits are insufficient and do not cover the full cost of providing the care needed by some people.

For most carers, the increasing cost of living has now eclipsed concerns about Covid-19. The financial impact of being an unpaid carer can be significant and many are struggling.

Upholding carers' rights

7.7 The two main elements of upholding the rights of carers under the Social Services and Well-being (Wales) Act 2014 are the right to an assessment and, if eligible, provision of the agreed support. From what we have been told, many carers are not having their rights upheld. This is recognised by local authorities, who are taking action to address it. In terms of the law, carers believe the Act is all that is needed. Implementation and enforcement is the weakness.

7.8 Carers' assessment is a problem, with significant waiting lists and delays in some areas. Assessments are not always done as quickly as the carer and the local authority would like. In some cases, assessments are not being offered to carers when they should be. Reasons include the backlog which accumulated during the pandemic and, while several authorities have taken action to tackle this, the recruitment and retention of social care staff continues to hamper their efforts. There also appears to be some inconsistencies in the approach of individual social care practitioners in offering an assessment.

7.9 While these points explain why not all carers' rights are upheld, there is a broader issue underpinning the ability to uphold rights under the Act. Before rights can be upheld, a carer must be identified and engage with social services or, in some areas, the third sector organisation commissioned to help carers on its behalf. This is not as straightforward as it sounds. Not everyone who cares for someone considers themselves to be an "unpaid carer"; and for a variety of reasons, some people do not want to engage formally with social services. Despite the efforts of local authorities and what some have achieved in identifying more unpaid carers, there is without doubt a body of carers with unmet needs.

7.10 Based on a sample of 300+ carers who responded to the online survey, there is a significant lack of awareness of carers' rights. Just 1 in 4 (25%) said they are aware of their rights. The majority – 45% - said they did not know their rights while the remaining 30% were unsure or did not know. Even some carers who had had assessments and received support did not know this was their right. A lack of awareness reduces the number of carers who seek help. It also affects a carer's ability to challenge local authorities when assessments are not offered or if support is not forthcoming.

7.11 Local authorities involved in this review are, to varying degrees, proactive in trying to reach out to unpaid carers to be able to identify and help more of them. However, identifying carers is not, and should not be seen as, the responsibility of social services alone. For adult carers, the NHS – primary care and hospitals – have a role to play as part of the more integrated health and social care system the Welsh Government is seeking to achieve. From feedback received, health services can do much more. For young carers, schools and colleges are critical partners. They already do much but the task in ongoing.

There are waiting lists for carer's assessments in most areas, which prevents carers having the support they need. Many carers are not being offered assessments.

There is a significant lack of awareness of carer's rights under the Act. Before any rights can be upheld, unpaid carers must be identified and engage with social services. For a variety of reasons, some are reluctant to do so.

Local authorities are proactive in trying to reach carers but recognise there is more to do. While the Act relates to social services, identifying unpaid carers is not their responsibility alone. GP surgeries and other health services, including hospitals, should play a much bigger role as part of a more integrated health and social care system.

Meeting carers' needs

7.12 The second element of upholding carer's rights is meeting their needs i.e. what was agreed in the carer's assessment. While many carers are supported after assessment, some report delays, sometimes weeks or months, before having support or support not being available or support which they deem unsuitable to their needs. Some carers reported problems with the care and support for the people they care for which, in turn, can impact on the carers themselves. A small number cited difficulties because of the cared-for person refusing support or a lack of help from sibling family members.

7.13 Based on the sample of carers, there is a deficit in meeting carers' needs. Fewer than 1 in every 10 carers (7%) said they have all the support they need while 14% have most of the support they need. Just under half (47%) said they have some of the support they need. One in every 3 carers (32%) said they do not have any of the support they need. The position for young carers was slightly better but caution is advised due to the small sub-sample. Some individual carers described having to "fight" to meet their needs and failures of local authorities to meet needs.

7.14 Respite care was the need mentioned most frequently by both local authorities and carers. There is a recognised lack of provision or a lack of suitable respite provision. It was outside the scope of this study to capture a detailed picture but from discussion, it is safe to say the picture differs from area to area.

7.15 Of all that can be done to help unpaid carers to protect their health and well-being, respite is probably the most important. It can take different forms and work in different ways. The assessment of a carer's needs made with their input, together with a more flexible and creative approach by local authorities to achieving the outcomes a carer wants is important.

7.16 Parts of this report describe a wide range of action being taken by local authorities to identify and meet the needs of carers and young carers and what some are doing to improve the way they work. The overall impression gained from discussions with staff in a variety of roles linked to carers and/or young carers is one of commitment and proactivity in trying to meet carers' needs. The report also describes what carers want and need. There is much is common between the two, but also differences. Carers emphasise the need for improvement and for more to be done to meet their needs.

While many carers have support, feedback from the large sample of carers reached by this review indicates a deficit in meeting carer's needs. Some of this might stem from the lack of awareness of carer's rights and the help available and how to access it, but some reflects a lack of support provision or suitable provision where carers live. Respite care is the most significant unmet need. This report describes what they need and includes suggestions for improvements which would help unpaid carers.

Recognising and valuing unpaid carers

7.17 Some carers were vociferous about the lack of recognition they get, and the lack of value placed on what they do. This is not only recognised by local authority staff but reinforced, saying unpaid carers play a vital, often unseen, and undervalued, role in the care system. Their health and wellbeing is important. If they cannot continue to do what they do, health and social services must step in to help, thus adding to the pressures on an already stretched system. Even a small additional number of people requiring statutory services (domiciliary care or residential) could have significant financial impacts. The unpaid carer is their [the cared-for person's] absolute 24/7 lifeline and commissioners rely on them.

The role of unpaid carers – young and old - is often unseen. Local authority staff and carers agree the contribution they make to the social care system is undervalued and is not recognised sufficiently well for what it does in preventing or delaying the need for statutory services to step in to provide care and support. Action to address this needs to consider the education and training of professionals such as social workers as well as the day-to-day operation of social services and health services.

Bringing about change

7.18 It is fair to say there is scepticism among carers. Some doubt as to whether anything will change because of the review and this report. Some carers said they have given their views before but say it has made no difference.

7.19 There is an opportunity for this report, the result of a project led by the Association of Directors of Social Services Cymru, to be the foundation for a co-ordinated national programme of action and sharing good practice across all local authorities, to improve what is done to help unpaid carers and to ensure their rights under the Social Services and Well-being (Wales) Act 2014 are upheld and their needs met.

Unpaid carers question the value of reviews where they fail to result in improvements across Wales. The initiatives by local authorities and what carers have said they need provide an opportunity to develop a co-ordinated national plan of action and sharing of good practice.

Appendix 1: Online survey - questions

1. We are looking at the experiences of young carers, young adult carers and older people who look after others as an unpaid carer. Are you:

    - Under 18.
    - Between 18-25 years of age.
    - More than 25 years of age.

2. Thinking about your needs as an unpaid carer, please select one of the following statements which best matches what you feel about the support you currently receive:

    - I have all the support I need.
    - I have most of the support I need.
    - I have some of the support I need.
    - I do not have any of the support I need.

3. What more could be done to support you as an unpaid carer which would improve your well-being?

    [open text response]

4. Based on your experience of getting help as an unpaid carer, what could be improved to make it easier and/or quicker?

    [open text response]

5. Are you aware of your rights; in other words, what you are entitled to as a carer under Social Services and Well-being (Wales) Act 2014?

    - Yes
    - No
    - Not sure or don’t know

6. Finally, is there anything else you would like to say about being an unpaid carer or the help you need?

    [open text response]