social care
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Review of evidence relating to unpaid carers’ needs assessments in Wales

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Key findings

- Most of the literature and evidence in relation to carers' needs assessments relates to adults rather than young carers. Additionally, there is little evidence in relation to COVID-19 and assessment processes, but rather more general information about support for unpaid carers.
- Confusion around terminology for carers' needs assessments and 'what matters' conversations exist for carers, who may not know if they are having a needs assessment. The different application of the terms makes understanding and comparing data on carers' needs assessments difficult.
- Barriers to accessing assessments includes unpaid carers not identifying themselves as such, because they see caring as part of their familial/spousal role or because they, or the person they care for, feels shame or stigma. Individuals may not be identified as carers by services and professionals that should signpost them to services or assessments.
- A barrier is a lack of timely information or advice, with Carers Wales (2020a) finding the percentage of carers who have been given or seen information had fallen over the previous three years (prior to COVID-19). There is confusion for carers as to 'where to start' if they need help.
- Some groups are more at risk of not accessing information that would be relevant to them. This includes people caring for children with additional support needs, carers not in employment and/or seeking employment, young carers and carers of people living with dementia. Language barriers, sensory impairments and limited internet access are also identified as potential barriers to accessing information.
- Delays in accessing assessments or not meeting the criteria for support were significant barriers. Where people felt the system was too hard to navigate or that they would not get satisfactory support anyway, there was a sense of disillusionment and a reluctance to seek assessment or support.
- Enablers to accessing assessment include an effective first point of contact with highly-trained staff, well-designed online resources, and carers' groups where carers can get peer support to navigate the system.
- Third sector organisations play an essential role in identifying and providing support to carers. Their role in providing and sharing information and making information accessible to specific groups is highlighted, as is their pivotal role during the pandemic.
- COVID-19 has resulted in an increase in the number of carers and they have found it difficult to access assessments. Information has had to be provided remotely, but any direct contact from professionals was appreciated by carers.
- It is essential the carers feel heard and are treated with respect during the assessment process, and doing so can help take down barriers created by previous negative experiences. Conversations have not always occurred in private spaces, making carers unwilling to be open.

- The knowledge and attitude of people conducting assessments affect how well they are perceived by carers. Carers are also aware of time and resource pressures and can feel under pressure to make decisions quickly or feel they have to fight for services.

Introduction

The Social Services and Well-being (Wales) Act 2014 enshrined a number of rights for unpaid carers in Wales. Since the Act came into force in 2016, work has continued to improve the lives of carers in Wales. This includes the consultation by the Welsh Government on the Carers' national action plan for Wales (Welsh Government, 2020a), a Government response to that consultation (Welsh Government 2021a) and a resulting new **Strategy for Unpaid Carers** launched in March 2021 (Welsh Government 2021b).

The focus of this rapid review is on the barriers and enablers to accessing carers' needs assessments in Wales and is part of the continued work to understand how to improve the quality and consistency of support for unpaid carers as identified in the Strategy for Unpaid Carers (Welsh Government 2021b).

Analysis of the 2011 census estimated that there were 370,000 carers in Wales, representing 12 per cent of the population. Of these, 54,000 provided 20–49 hours of care per week and 104,000 provided 50 or more hours (Office of National Statistics, 2012). There were approximately 30,000 unpaid carers under the age of 25 in Wales, with the principality having the highest proportion of unpaid young carers under 18 in the UK (Census 2011, reported by Welsh Government, 2021b).

The Social Services and Well-being (Wales) Act 2014 was ground-breaking in creating a legal duty on local authorities to carry out needs assessments for carers and to meet their eligible needs. However, local authority data suggests that many carers are not getting their needs assessed or getting the support needed. Of those that are invited for an assessment, just under 50 per cent refuse that assessment (Welsh Government, StatsWales, 2019).

This review will therefore focus on the barriers and enablers to accessing a carers' needs assessment as well as the experiences of those who have had an assessment. The review covers the period from 2016 and whilst there is some information in relation to the period since the 2020 COVID-19 lockdown. It should be noted that most of the literature and information predates the pandemic so there is a specific COVID-19 section that reports evidence from this period.

Review questions

The following research questions have been used to guide this review:

- What does the evidence tell us about barriers and enablers for unpaid carers in accessing support?
- What does the evidence tell us about why unpaid carers in Wales are not accessing carers' needs assessments when they are eligible to do so?
- For unpaid carers in Wales who do access assessments, what is their experience of that assessment? What went well and what could be improved?

Search criteria

The search criteria were based on the questions above, a review of background documents and discussions with the reference group, which included Social Care Wales and the Welsh Government.

Sources

A combination of the search terms presented in the text box below were used to search the following databases:

- Social Care Online (UK focused and includes specific Wales tagged content)
- Core (open access research papers)
- Social Systems Evidence
- Google Scholar
- Google

These specific websites were also searched: Welsh Parliament, Welsh Government, Social Care Wales, Care Inspectorate Wales, Carers Trust Wales, Carers UK, and Wales School for Social Care Research. The Reference Group also provided some papers for us to review. Snowballing was used to identify additional references from key studies

Population: "carer" OR "informal care" OR "unpaid care"

AND

Intervention: "carers' assessment" OR "assessment" OR "support" OR "access to services" OR "service uptake" OR "policy"

AND

Geography: Wales OR Welsh

Screening criteria

The searches identified 234 potential references to screen for inclusion in the review. We used the screening criteria in the table below to screen the available references for inclusion. This identified 40 papers to review, 28 of which are mentioned in the body of this report. These are roughly split into review documents (16) and context documents (12) although there is overlap.

Criteria	Inclusion/exclusion criteria
Population	Carers; parent carers of children with disabilities; young carers **Exclude**: kinship carers
Intervention	Carers' assessment; access to support, service uptake
Evidence type	Empirical research evidence; views and experiences research
Location	Wales; also include if about other areas of the UK including Wales.
Date	2016 onwards

Measuring the Mountain stories

In addition to the review of literature, an analysis of the **Measuring the Mountain** stories (2020) was undertaken.

The specific aim of Measuring the Mountain, as outlined in the proposal to Welsh Government, was:

> *'To understand the early impact of the Social Services and Well-being (Wales) Act 2014 and people's experiences of social care, particularly the factors that contribute to whether experiences are negative or positive, so that recommendations can be made that will improve wellbeing outcomes for people who need care and support and carers who need support.'* (Iredale and Cooke, 2020, pp7)

Participants were asked to:

> **Tell us a story about an experience of needing care or support, or of being a carer, that you have had in the last 12 months.**
>
> *This could be about advice, care, or support for you, or someone you know, or your experiences as a carer. We recognise that care and support services can relate to many different aspects of a person's life, so please feel free to tell us about community activities, school, health matters, housing etc.*

The database records 474 stories which were gathered during the 2019−2020 phase of the project. These stories were analysed for this review with 200 stories found to be relevant to the research questions.

- 149 stories related to barriers and enablers to accessing support
- 51 stories related to carers' experience of assessment

It should be noted that participants in Measuring the Mountain were not being specifically asked about carers' needs assessments. Within this total, 109 referred to barriers in accessing an assessment/support, 40 to enablers in accessing an assessment/support, 39 to negative experiences of assessment and 12 to positive experiences of assessment. Examples of stories have been used throughout this review. A breakdown of the themes identified within each of these four headings as well as the number of stories within each theme is provided in the Appendix. Some caution should be taken in interpreting the data quantitatively as the sample is not random and is self-selecting, meaning there could be bias in relation to the carers who shared their stories and some groups could be over or under-represented.

The analysis of the Measuring the Mountain stories has provided a helpful insight into some of the key issues. This review has both confirmed and expanded on the work of Cooke et al (2019) who made an overall critical assessment of carers' needs assessments after reviewing the stories, noting that the vast majority were negative, with only one positive. The current review of the stories suggests that the existing literature does mirror closely the reported experiences of carers. The limitation of these stories is that they can lack context, and it would be useful to better understand the 'journey' of carers, prior to and after assessment. This would help to better understand the needs of groups least likely to be offered or accept an assessment.

Current guidance on carers' needs assessments

Since the introduction of the Social Services and Well-being (Wales) Act 2014, carers have an equal right to an assessment and support as those that they care for. Carers no longer need to demonstrate that they provide a substantial amount of care on a regular basis to be considered as a carer (Welsh Government, 2020a). Carers of all ages have this right and so it applies to adult, young adult carers and young carers.

Definitions

The Social Services and Well-being (Wales) Act 2014 describes a carer as **someone who provides unpaid care to an adult or disabled child**. The cared-for person may be a family member or a friend, who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

A **young carer** is usually defined as a child or young person under 18 years old who spends time looking after or helping a family or household member that would find it difficult to cope without this help (SCIE, 2020). Most young carers look after a parent or a brother or sister. A young carer may be caring for more than one person, for example, a parent and a sibling.

A **young adult carer** is a carer 'in transition to adulthood' and aged between 16 and 25.

Guidance to support carers in Wales

This section briefly sets out or signposts to some of the existing guidance in relation to carers. To understand both barriers and enablers to carers accessing a carers' needs assessment, it is helpful to consider what the process *should* look like according to existing guidance. The guidance described is for carers of all ages rather than being separated into young carers and adult carers. Guidance exists for local authorities, practitioners and for carers.

Social Services and Well-being (Wales) Act 2014 Part 3 Code of Practice (assessing the needs of individuals) (Welsh Government, 2015) provides guidance for local authorities and practitioners and provides information around carers' needs assessments including:

- A process for assessing the needs for support of a carer.
- A process of assessment that will apply to carers.
- A process of review and re-assessment that will apply to assessments.

(Welsh Government, 2015, pp3)

There is also information on the National Assessment and Eligibility Tool, the responsibility of those with first contact with a carer, the basis of assessment and eligibility and refusal of assessments.

A suite of four practice resources have been developed by the Institute of Public Care and Social Care Wales (2019) **to assist practitioners to assess carers' support needs**:

- **Resource A – Training Manual**. Guidance for trainers that provides information needed to run formal training sessions for practitioners.

- **Resource B – Training Slides**. A slide pack to assist trainers to develop training sessions.
- **Resource C – Practitioner Self-Training Workbook**. A reflective workbook for practitioners who have not received a formal training session, to read, reflect on and work through to improve their practice with carers.
- **Resource D – Practitioner Toolkit.** A number of practice tools in one place that practitioners can select and apply to practice in the context of reflection.

Carers' organisations across Wales helped with the development of the toolkit, training manual and reflective training aid. They advised on the content and were involved in the editing process. Practitioners were also asked to comment on the resources, so the key people who will use these resources, carers and families and practitioners, have actively shaped them. These practitioner resources include assessment information for both adult and young carers.

A guide to getting an assessment in Wales (Carers Wales, updated 2020) is a resource produced for carers which sets out the legal requirements for assessments in a clear and user-friendly way. It covers both young and adult carers. It includes 'Questions to help prepare you for your carer's needs assessment'.

Current data on carers' needs assessments

Local authority data

Welsh Government local authority data can be viewed via the **StatsWales** data service. StatsWales has data on carers' needs assessments for the 22 local authorities for the years 2016–17, 2017–18 and 2018–19. Whilst there are some limitations with the data (see summary information on the StatsWales website for more details), it is helpful for tracking trends over time.

Table 1: Adults assessed by local authority and measure 2016–2019

Financial Year	Number of assessments of need for support for carers undertaken during the year	Of those, the number that led to a support plan	Number of carer assessments that were refused by carers during the year
2018–19	7,261	2,748	6,876
2017–18	6,602	2,568	6,546
2016–17	6,178	1,813	6,967

Source: Welsh Government, StatsWales **(**2019)

The data (reproduced in Table 1) indicates that the number of carers' needs assessments has been increasing each year as has the number of support plans. However, the number of assessments refused remains high. When compared with the number of carers identified in the 2011 census (370,000, with 104,000 providing 50 of more hours per week), a relatively small proportion of carers in Wales appear to be receiving an assessment each year.

The number of assessments

Carers Wales collects local authority data annually, with the most recent being 2019–2020 as reported in Track the Act Briefing 5 (2020). They asked all 22 local authorities how many carers had received either a carers' needs assessment or 'what matters' conversation in the past year. Twenty-one local authorities were able to provide this data, totalling 14,646 assessments and conversations. This was a decrease of 4,068 from the previous year. It was noted that a decrease in assessments and conversations was down across the board with the exception of Newport (who reported a 15,000 per cent increase from 71 to 1,136). This data is usefully considered alongside the Welsh Government data (StatsWales, 2019) as it includes the broader category of both carers' needs assessments and 'what matters' conversations, rather than assessments only.

The 'Front Door' to Adult Social Care (Wales Audit Office, 2019) analysed past local authority data and found that the number of carers receiving an assessment rose by 26.4 per cent over the period between 2008–09 and 2015–16. However, in the two years after the Act came into force the number of carers' needs assessments undertaken had reduced by 10.9 per cent.

Numbers rejecting assessments

The Welsh Government data indicates that a high proportion of carers that are offered assessments reject them (StatsWales, 2019). In 2018–19, 14,137 carers were offered assessments and 6,876 (49 per cent) rejected them. The data on rejection of assessments was not systematically collected for the latest Track the Act Briefing (Carers Wales, 2020), but of the two local authorities that reported rejected assessment or conversations, the rejection rate was 70 per cent and 68 per cent. It was noted that this was in stark contrast to the 8 per cent of carers that completed a survey for Carers Wales.

Number of support plans following assessments

Welsh Government data (StatsWales, 2019) shows that in 2018–19, of the 7,261 carers receiving assessments, 2,748 led to a support plan. This is 38 per cent of those assessed. Track the Act Briefing 5 (Carers Wales, 2020) found 2,967 received support in 2019–20. It highlights though that it is not clear whether the support given was part of a combined assessment (for the person being supported and for the carer) or if the support was specifically for the carer. Additionally, the local authority data is a helpful indicator of the number of people being assessed and supported, but not whether the carers felt that the support provided met their needs.

Surveys of carers

As well as data collected at a local authority level, there have been some surveys of carers in Wales since 2016. One of the strengths of these carers' surveys is that they can focus on particular groups of carers (for example, those caring for someone living with dementia), something that cannot be done with the local authority data available.

Carers Wales: Track the Act

Data from carers is collected by Carers Wales for its Track the Act briefings. The 2019–2020 survey reported in Track the Act Briefing 5 (2020) included 620 carers, representing all 22 local authority areas. All of the participants were over 18 and the survey closed prior to the COVID-19 lockdown. The survey is self-selecting (participants define themselves as carers) and is not random (all carers in Wales do not have an equal opportunity to take part) and so there are likely to be biases within the sample. However, the survey is useful to consider alongside other data and includes open-ended responses as well as the statistics.

Of those surveyed, only 14 per cent had received a carers' needs assessment or 'what matters' conversation in the financial year 2019–2020 and 72 per cent had neither been offered or received an assessment or conversation since the beginning of the Act. In terms of support, 62 per cent said they were caring with no support, including informal support from other friends or family, which was an increase of 5 per cent from the year before. When the support being received was broken down, 14 per cent received support via a council care package for the person they care for and 2 per cent from a council care package for the carer, 13 per cent paid for support themselves and 5 per cent received free support from charities.

Wales Audit Office

For its report **The 'front door' to adult social care services** (2019), the Wales Audit Office commissioned a telephone survey of carers, asking questions relating to what difference the Act had made to them. There were 550 responses and this covered all 22 local authority areas. Alongside this an online survey of third sector provider organisation received 22 responses.

Alzheimer's Society

The Alzheimer's Society (Allen et al 2020) found that national data on carers could not be disaggregated to better understand publicly-funded support for carers of people living with dementia. Similarly, most local authorities were also unable to provide information specific to support for carers of those living with dementia. Where it was possible to get this level of detail, it was often due to third-party providers and used for contract monitoring.

The Alzheimer's' Society undertook a survey of carers supporting people living with dementia before the pandemic (Allen et al 2020). Its report covers both England and Wales, with 319 carers completing the survey. Thirty-nine per cent reported having had a carers' needs assessment, 53 per cent had not had one and 8 per cent were unsure. Those from Wales reported having had an assessment most frequently (52 per cent) and those who had had an assessment were most satisfied with them in terms of how well they felt they were listened to (mean of 7.2 on a 10 point scale), how well their needs were identified (mean of 6.5 on a 10 point scale) and how much their situation was understood by the assessor (mean of 6.5 on a 10 point scale). So relative to England, people living in Wales who were caring for someone living with dementia did report better outcomes in relation to assessments. The sample size is small and the method of sampling is not random given the population of interest and so caution should be taken.

Barriers to carers in Wales accessing assessments

Caring for our Future: an inquiry into the impact of the Social Services and Well-being (Wales) Act 2014 in relation to carers found that:

> *'Many carers find it hard to get a carers' assessment; assessments are not routinely offered. When offered, there is a high number of refusals of assessments.'*
>
> **(National Assembly for Wales, 2019).**

A number of barriers have been identified in the literature and from the Measuring the Mountain stories in relation to the specific context in Wales since 2016. These are:

- Not identifying or being identified as a carer
- Access to information, advice and assistance
- Delay in accessing assessments or reviews
- Confusion over terminology
- Mismatch between expectations and outcomes

Each barrier is discussed in more detail below.

Identifying and recognising carers

The Strategy for Unpaid Carers (Welsh Government 2021b) has four priorities, the first of which is: 'Identifying and recognising carers'. The strategy highlights that 'Early identification of unpaid carers is an important step towards ensuring they can access the support they are entitled to' (pp14) and that this relates to both self-identification by carers and identification by professionals across statutory, private and third sectors.

Challenges around identifying carers or carers not seeing themselves in that role is a recurring theme in the Track the Act Briefing 5 data (Carers Wales, 2020a), in a number of reports by the Welsh Government (2020a; 2020b; 2020c; 2021a), and by other organisations including the Institute for Public Care, and Social Care Wales (2019a; 2019c; 2019d), Social Care Wales (2017), National Assembly for Wales (2019). The issue is of such importance, both in terms of self-identification and identification by health and care professionals, that is has been recognised as a 'key obstacle' (SCIE, 2018).

> *'When I was in college doing health and social care, we looked at services for people with caring roles. Research made me realise I was a carer for my mum.'*
>
> **(Measuring the Mountain stories, 2020)**

Some carers do not recognise themselves as 'carers' (Social Care Wales, 2017, Carers Trust Wales, 2019) and may go through a period of 'dawning realisation' (IPC & SC Wales, 2019a). Carers UK's Missing Out report provides evidence that this realisation can take a significant time, for example in Wales 55 per cent of carers took more than one year to see themselves as a carer and another 25 per cent took five years (Carers UK, 2016).

Other carers may **see the support they provide as a natural part of their relationship** with the cared-for person and be reluctant to come forward, meaning they do not access benefits or supports which may be available to them. This has been identified as being particularly true in relation to older carers (aged 80 years old or above) looking after a spouse or partner, LGBTQ+ carers, Black, Asian and minority ethnic carers, and carers of people with dementia or mental health issues (SCIE, 2018).

> *‘I’m a wife and a person who cares, I’m not a carer, I don’t really think of myself like that.’*
>
> **(Measuring the Mountain stories, 2020)**

Carers may also remain hidden because of a **sense of shame**, wishing to keep their business private, preserve the dignity of the one they are caring for or because the person being cared for does not want to involve outside agencies (IPC & SC Wales, 2019a). This has been found to be true particularly in the LGBTQ+ community (Welsh Government, 2020b). Evidence suggests that when the person or people being cared for refuse support from external agencies, this can place the carer in a difficult position (Measuring the Mountain stories, 2020).

There can also be **stigma or a sense of failure** around involving social services both for the carer and the person being cared for (National Assembly for Wales, 2019; Measuring the Mountain stories, 2020).

Stigma: Measuring the Mountain stories (2020)

‘I should have had more help with caring for him but I wanted to preserve his dignity.’

‘As a carer for my disabled son, I previously felt there was a stigma around having a social worker. My husband and I work full time and had never claimed any additional benefits or accessed additional services for our son.’

‘I didn't know what would happen and felt stigma attached to social services.’

’I work full time and care for my mother and father who are in their 80s. They both have refused help saying ...”our family will care for us”… My father is getting more and more frustrated with my very demanding mother with Parkinson's (that's what happens). However, he would feel he has failed if services were brought in.’

Carers in rural areas in Wales may have specific problems with **social isolation, poverty, lack of transport** and inaccessibility which makes it more difficult to identify and support people who may need help with their caring roles (Welsh Government, 2020b).

A key aspect of the 2014 Act is that a carer does not have to specifically request a carers’ needs assessment or self-identify as a carer to be offered an assessment. If a need for such an assessment is identified by a relevant professional working with that carer, one should be offered to the carer, or they should be signposted to the local authority (Welsh Government, 2020c). This signposting system opens up another route for carers who may not identify as such or who may be unaware an assessment or support may be available to them.

There is evidence that **professionals may not identify carers as such.** This includes both carers who do not identify themselves as such, but also carers who do identify as carers and would like their role to be recognised (Care Inspectorate Wales, 2020). Professionals who are involved with the person being cared for can play a key role in identifying carers, but can also act as a barrier with Measuring the Mountain stories (2020) recording instances of ‘missed opportunities’.

Missed opportunities: Measuring the Mountain stories (2020)

'My social worker once told me that because I can't hang the washing on the line or make a meal, I'm not a carer. I explained that her comments were inaccurate and inappropriate. I am a carer, the fact that I don't fit their limited definition of a carer only invalidates their limited criteria, it can never invalidate my labour, love and care.'

'The GP wouldn't listen to me even though I was with her all the time apart from school and they wouldn't ask my mum about her conditions. When I asked the GP to put me on mam's notes that I am her carer − so all GPs or specialists would know I care for mam − he said "nothing I can do".'

'I'm clearly disabled − I went to the GPs to get all my meds sorted. My husband's my main carer and has retired so I can have a life − which is huge to me, that he's done that. Nothing has been mentioned to him about being a carer and there have been no offers to or referrals made for a carers' needs assessment. We don't need loads of support but the areas we need help with are the ones we can't get.'

'I care for my sister, a social worker has been to see her, but they've never really been there for me.'

'I'm an immigrant, I didn't grow up here. Didn't know what support is available… Not offered any assessments or help.'

'Professionals need to be aware and make referrals.'

Responses to the Consultation on a carers' national plan for Wales found there was considerable support for the Welsh Government to deliver a national communications campaign to raise awareness amongst individuals that they are carers, that carers have rights, and to inform them of the options available for unpaid carers (Welsh Government, 2021a). Some respondents to the consultation also recommended the creation of a central register or list of unpaid carers which could be accessed by different agencies. Some responses called for a national form of identification for carers. There was also a call for a specific legal duty to be placed on education providers to identify young carers and young adult carers (Welsh Government, 2021a).

Young Carers

The issue of **identifying young carers** remains a concern (Care and Social Services Inspectorate Wales, 2017). Young carers can often remain 'under the radar' as many come from hidden or marginalised groups, such as children caring for a family member with mental illness or a substance dependency. They may remain hidden for reasons associated with family loyalty, shame and stigma, fear of bullying and not knowing who may be able to help them or offer support (IPC and SC Wales, 2019a).

Young carers have reported that they would like more people to understand their situation better and be able to talk to them about it, but UK wide evidence suggests that often no one at their school is aware of their situation (Social Care Wales, 2017). This relates to a wider concern regarding information sharing and data, that many providers do not know which of their pupils and learners have a caring role (Estyn, 2019).

As part of the 'Caring for our future' inquiry (National Assembly for Wales, 2019) the Association of Directors of Social Services described the challenge within local authorities to identify young carers. Some young people did not identify as carers, especially when there was another adult carer in the household. Their needs were described as often complex and 'intertwined with those of the cared for and other adults in the household' (pp59).

The responses to the recent National Carers' consultation (Welsh Government, 2021a) highlight that young carers can also face difficulties communicating with professionals because they are young and their caring role may not be recognised. Whilst training courses are available to raise staff awareness of the needs of young carers in schools, colleges and Pupil Referral Units, many have not received this training (Estyn, 2019).

The Welsh Government has provided funding for Carers Trust Wales to develop the guidance and tools for a national roll-out of ID cards for young carers to enable them to access the support they need from schools, surgeries, pharmacies and other professionals. A number of cards were **launched** across eleven local authorities in March 2021. Funding has been made available to local authorities again in 2021-22 to work in co-production with Welsh Government and CTW on further roll out the scheme in order to achieve national coverage of a young carers ID card, by end of March 2022.

Access to information, advice and assistance

In support of carers: carers engagement overview report recognises the vital importance of timely access to information, advice and assistance (IAA) and identified it as a key theme repeated by carers (Care and Social Services Inspectorate Wales, 2017). Providing IAA is the second priority in **Strategy for unpaid carers** (Welsh Government, 2021b) with supporting evidenced in the responses to the consultation on that strategy (Welsh Government, 2021a).

However, there is evidence from several sources (Social Care Wales, 2017; National Assembly for Wales, 2019; Care Inspectorate Wales, 2020; Care and Social Services Inspectorate Wales, 2017; Carers Wales, 2020a) that too often, **people are unable to access the right IAA at the time they need it**, including people who are in contact with the types of services that might be expected to signpost to a carers' needs assessment or wider services for carers:

> *'As a carer attempting to get understanding, advice, support and emergency care from the 'community' – such as GP, public transport, social services, dentist pharmacies and hospitals – can be very challenging, exhausting and beyond stressful.'*

(Social Care Wales, 2017 pp28)

> *'Most carers are not aware of the Social Services and Well-being (Wales) Act 2014 or their rights under it, particularly regarding the right to a carer's needs assessment. There is also a lack of awareness of the Act and carers' rights amongst professionals, including social services staff.'*

(National Assembly for Wales 2019, pp21)

> *'It suits them that carers don't know about their rights, because informing them means carers know what they're entitled to and what they're not getting from their councils.'*

(Welsh Audit Office, 2019 pp 28)

The carers survey conducted by Carers Wales as part of Track the Act Briefing 5 (described in **Surveys of carers, pp11**) records survey results from 620 adult carers (Carers Wales, 2020a). According to the survey responses:

- The percentage of carers who have seen or been given information has fallen over the last three years:
  - 2019–20 – 38 per cent (note survey closed before COVID lockdown)
  - 2018–19 – 45 per cent
  - 2017–18 – 53 per cent
- Only 10 per cent of carers have received information or advice services from local authorities over the period April 2019–March 2020
- More than two fifths (41 per cent) had not heard of a carers' needs assessment before doing the survey

> *'I have found it very difficult to find out what I am entitled to. It seems that those who can help are more interested in saving money rather than helping the people who need it.'*

(Carers Wales, 2020a)

The consultation on a carers' national plan for Wales (Welsh Government, 2020a) recognised that knowing how or where to access information can be difficult for carers and **that for many carers there can be confusion as to where to start** if they want to find out more and get help with their caring responsibilities.

Issues commonly identified in the literature are:

- Too often information on IAA services is not aligned or consistent across Wales (Allen, et al., 2020; Care Inspectorate Wales, 2020; National Assembly for Wales, 2019). Care Inspectorate Wales call for leaders and managers to work towards integration of IAA (Care Inspectorate Wales, 2020)
- Accessing information at a time of crisis or stress is particularly difficult for carers (Care and Social Services Inspectorate Wales, 2017; Care Inspectorate Wales, 2020)
- Some carers would like information about other people's stories or journeys as well as about services, particularly those caring for someone with dementia (Social Care Wales, 2017)
- Some groups of carers have been identified as being less likely to access information or find the information unsuited to their needs:
  - People caring for children who need additional support are 15 per cent less likely to see information than people caring for parents (Carers Wales, 2020a)
  - Unemployed or economically inactive carers. Only a third (32 per cent) have seen information related to their caring role. Track the Act Briefing 5 highlights that this group may have the most intensive caring role given their inability to work in addition to care and should be a priority audience for information (Carers Wales, 2020a)

  - Young carers (National Assembly for Wales 2019)
  - Those caring for someone with dementia (Social Care Wales, 2017)
- The format and language of IAA can act as a barrier for some groups who may struggle to understand or access the IAA even once they know where to find it:
  - Language barriers, including the need for Welsh language (Welsh Government, 2020a)
  - Formats that do not support people with sensory impairments (Allen K., et al, 2020)
  - Lack of, or reduced access for people with no or limited internet access (Welsh Government, 2020a)

Information, advice and assistance: Measuring the Mountain stories (2020)

'Of all the services I have ever been in contact with, not one professional has ever been able / has offered any offer of services or help available for my son or my family.'

'*It's a minefield and even though I work in the system, I don't know how to get help.'*

'There should be one person you go to for everything – we don't know what to do or where to go – housing, finance, social services, it should all be together.'

'Everything is found out by word of mouth, by accident.'

'I have had to look harder to get help and I have struggled to find what benefits I can access to help me financially. I have to pay for the respite care myself. There was not enough sig posting for me as a carer.'

'*They've placed a lot of reliance on technology and forgotten that a lot of us don't have the internet, and even if they do, they need pre-knowledge of an organisation as they're unlikely to come across it by fluke. This doesn't seem to be understood by these organisations. I'm very, very angry.'*

There was also evidence to suggest that not having a recognised diagnosis for the person a carer is supporting had prevented people from being able to access support. Parents who are carers of children with complex needs, autism or behaviour that challenges have sometimes seen a diagnosis as a gateway to services (Care and Social Services Inspectorate Wales, 2017). In turn, the **lack of diagnosis and/or a social worker** for both adults or children can be a barrier to signposting to formal support for both the person being supported and the carer.

Lack of diagnosis: Measuring the Mountain stories (2020)

'I have applied for carers allowance and that has been rejected because of my husband's status … and when I ask for more information no one can clarify the problem. I find it very difficult to understand and navigate the system.'

'*Because he didn't fit the criteria, he didn't have a social worker and that made getting any other support really difficult. Some professionals know that you know your son. Others view you as difficult, you feel like you're being a pain.'*

'There does not seem to be any continuity. There is no available support to help with managing my son's behaviours, as in order to get support you have to have a diagnosis.'

Delay in accessing assessments or reviews

Evidence from responses to the Consultation on a carers' national plan for Wales (Welsh Government, 2021a), Track the Act Briefing 5 (Carers Wales, 2020a), Carers Engagement Overview Report (Care and Social Services Report Wales, 2017) Care Inspectorate Wales (2020), and Measuring the Mountain (2020) suggests that delays in initial assessments and in re-assessments can both act as barriers. Whilst there is no definitive timescale prescribed in the Social Services and Well-being (Wales) Act 2014, part three of the code of practice states, 'The person, and people involved, should be kept informed of the progress of the assessment and expected timescales for completion of the assessment process' (Welsh Government, 2015, pp10). It was not clear from the literature what caused the delays, if there was a mismatch between expectations of carers and likely timescales, and how a re-assessment should be triggered – whether this was the responsibility of the carer or other services. It is hard to determine which carers that have not had an assessment recently are waiting for one, rather than not having yet requested one or been referred for one.

Responses to the Consultation on a carers' national plan for Wales reported that many carers had not had a carers' needs assessment, or review of their assessment within the last 12 months (Welsh Government, 2021a). This was in line with the Track the Act Briefing 5 where 86 per cent of carers had not received a carers' needs assessment in the financial year 2019–20 (Carers Wales, 2020a). Carers are not being routinely offered an assessment of their needs (Care and Social Services Inspectorate Wales, 2017) and can wait a long time for an assessment with some having to make repeated requests for one (Care Inspectorate Wales, 2020). Care Inspectorate Wales further found that carers' rights to assessments were not always upheld and state that local authorities should ensure their duty to offer assessments to carers is improved.

> *'I put in for a review from social services when I was pregnant for me and dad. Dad was making things difficult – wasn't happy about my pregnancy. They said that there was a backlog and the review still hasn't happened… You've got to do it yourself, that's essentially their advice as we've got really long waiting lists.'*

(Measuring the Mountain stories, 2020)

> *'The reassessment process is disgusting and the months you are left without answers is a huge cause of stress and upset because your life is being left in a limbo. There needs to be a timescale on these things.'*

(Carers Wales, 2020a pp14)

Some young carers' services also have a waiting list for support and it is unclear how young carers are then supported whilst waiting to access the service (Care and Social Services Inspectorate Wales, 2017).

Confusion over terminology

Institute of Public Care and Social Care Wales (2019, pp5) 'What matters' conversations and assessment

'A 'what matters' conversation is a targeted conversation relating to any assessment process.

It refers to a skilled way of working with individuals to establish the situation, their current wellbeing, what can be done to support them and what can be done to promote their wellbeing and resilience for the better.

It's not an assessment in itself: it's a way of carrying out the assessment, with the practitioner having the right type of conversation to identify with the individual:

- How they want to live their life
- What might be preventing that
- What support might be required to overcome those barriers.'

There is **confusion surrounding the different terminology** used by different local authorities (Carers Wales, 2020a; National Assembly for Wales, 2019). Some use a 'what matters' conversation as a precursor to a carers' needs assessment, whilst others use it as their legal carers' needs assessment. This can lead to a lack of clarity about whether carers have received their assessment or not. It can also lead to **discrepancies in how assessments are recorded** and makes comparisons between local authority statistics more difficult. Track the Act Briefing 5 records that there were 14,646 carers' needs assessments (or 'what matters' conversations) according to the 21 of 22 local authorities who were able to provide data for the financial year 2019–20 (Carers Wales, 2020a). It is unclear how many of each actually took place and if in how many cases they are combined. In comparison, the Welsh Government also collects data from the 22 local authorities (StatsWales, 2019) (although this is not available for 2019–2020), but only for carers' needs assessments and not for 'what matters' conversations. Their figures vary quite substantially to the Track the Act figures. This lack of clarity becomes even more relevant when looking at outcomes following an assessment or conversation.

The briefing reports that in Carmarthenshire local authority, 664 of the 1,065 who had an assessment received a support package (62 per cent) whilst only 68 of 1,517 (4 per cent) did in Caerphilly. From the additional evidence provided by local authorities, it can be determined that part of the reason for this discrepancy is that the local authorities who are doing more 'what matters' conversations are less likely to provide a support plan than those who are predominantly doing carers' needs assessments (Carers Wales, 2020a).

If comparison between local authorities or between different carer groups (e.g. young carers, carers of people living with dementia) are of relevance, then it is important both carers and local authorities are clear about what assessment is taking place and that data can be fairly compared.

The Caring for our future inquiry (National Assembly for Wales, 2019) found that **sometimes carers did not know that they were being assessed**. The status of any conversations and the potential outcomes of those conversations is not always made clear and so people may not know what questions they should be asking or how much information to give. Not knowing they have been assessed will also impact on the findings from carers' surveys, as numbers could be underestimated.

The term 'carers' assessment' has been found to be unhelpful, leaving some carers feeling that this was something which was 'done to them' rather than a partnership between them and practitioners (Care Inspectorate Wales, 2020). It is this type of language and power imbalance that the 'what matters' conversations seek to address, but how the two work in practice, is causing some confusion.

The **term 'carer'** is also seen to have created confusion, particularly because of national media and government communications using the term carer, when referring to a paid care worker. The weekly National Clap for Carers during 2020 was seen by some as a major cause of confusion. Some disagreed with the term carer being used by other groups, because they were not unpaid carers (Welsh Government, 2020a).

Mismatch between expectations and outcomes

A loss of confidence in the system can be sensed through some carer responses and this impacts of whether they will seek or take part in an assessment. This sense of '*No point, there is nothing to help me*' (Carers Wales, 2020a, pp 14) may be better understood in light of statistics regarding those who go on to receive a support plan following a carers' needs assessment.

The Welsh Government data (StatsWales, 2019, see **Local authority data** section, pp10) shows that in 2018−19, 7,261 assessments were undertaken and that of those, 2,748 (38 per cent) led to a support plan. Analysis of 2019−20 data from local authorities for Track the Act Briefing 5 examines on the number of carers getting support or direct payments following an assessment. There are some gaps in the data, but they show great variation in the proportion of carers receiving a support package following assessment or a 'what matters' conversation from 4 per cent to 62 per cent. The briefing concludes that this lack of direct support in some areas may be diminishing confidence in the assessment among carers (Carers Wales, 2020a).

As part of a survey undertaken by Carers Wales in 2017−18, of those that had requested or been offered an assessment, 37 per cent did not meet the eligibility criteria for help or support as a result of that assessment. In written evidence to the Caring for our future inquiry, Carers Wales described this as 'extremely disappointing' given that the vast majority of respondents had been caring for over a year with significant caring responsibilities (National Assembly for Wales, 2019). This was also highlighted in findings from the Measuring the Mountain stories.

> *'Apparently his dementia is not "serious" enough as yet, therefore we have to "just get on with things", but there is not a day goes by that I come home and something or other has occurred which requires my attention to put right.;*
>
> **(Measuring the Mountain stories, 2020)**

Care Inspectorate Wales found that the duty to provide support before people reach crisis is not consistently embedded in practice across local authorities in Wales. At times managers misunderstand their duty and interpret ineligibility for care and support plans as ineligibility for support to promote wellbeing. The Inspectorate recommends that the Welsh Government should review and provide clarity in this area (Care Inspectorate Wales, 2020).

Eligibility criteria for carers allowance was also raised as an issue in responses to the Consultation on a carers' national plan for Wales (Welsh Government, 2021a). Carers cannot receive Carer's Allowance if they are in full-time education, or even if a course is part time but attendance is required for 21 hours or more each week. This not only affects young adult carers but adults who wish to return to education.

The focus of this review is not on the outcome of assessments or the support that is provided to those who meet the criteria, however, the perceived usefulness of this support and the wider system has an impact on whether people will seek out an initial assessment or a re-assessment as is highlighted by the quotes below. Some of these stories echo the findings of the National Assembly for Wales (2019) who reported that carers had to 'fight' for services, and that this should not be necessary.

Mismatch between expectations and outcomes: Measuring the Mountain stories (2020)

'The councils or government bring forward various provisions or Acts to help carers but because of cuts they just become words not actions.'

'There's no funding anywhere for this group of children or for those that support and care for them.'

'The paediatrician referred us to social services and a social worker came to our home. They came three or four times and asked lots of questions, and at the end they said we're not eligible for any support. It was a complete waste of time, no help was given and the process gave us hope which they dashed. I never want to get help again... How can we trust people? If we need anything in the future how can we trust them? They don't do anything to help, it's why we feel sad.'

Track the Act Briefing 5 (Carers Wales 2020a)

'I haven't requested another one due to a bad experience when my last one was carried out.' (pp14)

'It is a losing battle to get any help or support. It makes me feel let down and exasperated on top of the way I already feel.' (pp 15)

'I don't see the point, as always the same battle and lack of support.' (pp14)

'We have been promised up to six weeks respite, but none has been delivered in two years.' (pp15)

Evidence indicates that there is some tension between emphasising the value of having a carers' needs assessment to carers, as well as to professionals who may signpost carers to have an assessment, but also managing a carer's expectations (Carers Wales 2020a; Care Inspectorate Wales 2020; Measuring the Mountain stories 2020). Measuring the Mountain stories (2020) additionally highlight that the needs assessment is one part of a wider, sometimes hard-to-navigate system. Issues are not only about the assessment, but the whole 'journey' carers have experienced. Care Inspectorate Wales identifies that 'the emphasis in legislation of the overarching duty to promote wellbeing, with limited explanation, has contributed to a mismatch between carers' expectations and available resources' (Carer Inspectorate Wales, 2020, pp5). It is not clear from the evidence if particular groups of carers are more likely to experience a mismatch between expectations and outcomes than others.

Enablers to carers in Wales accessing assessments

A number of enablers have been identified in the literature and supported by the Measuring the Mountain stories (2020) in relation to the specific context in Wales since 2016. Where possible, examples of those enablers have been drawn on to highlight existing practice that supports access to and/or uptake of assessments.

These are:

- Access to timely and relevant information, advice and assistance
- Third sector organisations
- Advocacy
- Diverse and flexible provision of support
- Well-trained frontline staff and the sharing of best practice

Each enabler is discussed in more detail below.

Access to timely and relevant information, advice and assistance

A clear focal point from which carers can access up-to-date information, advice and support is a key factor in providing positive support for carers (Carers Trust Wales, 2019). In an analysis of Measuring the Mountain stories, knowledge and information were seen as key components to building an individual's confidence and ability to share power or work more closely with providers (Iredale, 2020). Many of the positive experiences recorded described straightforward processes, offers of information and support with minimal administrative burden.

The 'front door' to adult social care (Wales Audit Office, 2019) recognises that an effective information, advice and assistance (IAA) service will identify when someone needs an assessment or more specialised help (Wales Audit Office, 2019). It found that the best local authorities have highly-trained first-point-of-contact staff who filter telephone calls, e-mail and service requests as a single local-authority 'front door'. Access to services is encouraged and promoted proactively and comes both directly from people and their carers, but also partners such as hospital staff and GP surgeries and other local authority services including tenancy support teams and housing officers. The report goes on to highlight examples of good practice:

- IAA staff in Denbighshire County Council use a 'resource wheel' which is a tool that helps understand people's circumstances, strengths and capabilities.
- Authorities such as Denbighshire County Council, through its single-point-of-access (SPOA) team and Carmarthenshire County Council's Delta Wellbeing service provide bespoke, multi-skilled call centres acting as a single gateway to services.

For young carers, Estyn (2019) highlights the essential role of secondary schools, colleges and pupil referral units (PRUs) in meeting the needs of young carers and having robust systems in place to identify young carers. Best practice by secondary schools, colleges and PRUs involved tracking the wellbeing needs of each young carer regularly and adapting their provision carefully to meet individual needs. It was also found that only a minority of the schools, colleges and PRUs track and report on the progress young carers make compared with their peers. It is known that young carers are more likely to miss school or experience problems at school or with their academic progress than their peers (National Assembly for Wales, 2019).

Websites and social media

Although information should not be shared solely through digital means, the expansion of social media content and access will inevitably become the preferred method of support and advice, and local authorities will need to recognise and support this change (Care and Social Services Inspectorate Wales, 2017). In terms of website design, **The 'front door' to adult social care** (Wales Audit Office, 2019) recommends that good practice in websites should include the following (Wales Audit Office, 2019):

- Ensure 'Contact us' sections are clearly and actively promoted on every web page and include information about where to find solutions
- Clearly display an emergency contact number to a 24-hour helpline and information about the opening hours of contact centres/offices
- Be fully bilingual, including documents, resources and forms accessed via links
- Include details of when the pages were last updated to ensure information is up to date
- Avoid jargon and is write in plain English with clear easy-to-follow instructions
- Clearly set out the services that are available, how to seek help and include embedded links to automated Dewis Cymru searches for locally-available services.

Wales Audit Office (2019) found only 6 per cent of carers had found information on IAA services themselves and did not require the help of professionals, suggesting that whilst helpful, websites may not be acting as a gateway for the majority of carers.

Dewis Cymru

A website that aims to help people seeking advice and assistance and promoted as 'the place for information about wellbeing in Wales' (Wales Audit Office, 2019, pp15). It is maintained by Data Cymru and is supported by all 22 local authorities, with each contributing towards its maintenance and development. Across Wales the number of searches carried out using Dewis Cymru's resources directory has steadily increased and in January 2019 was almost 400 per cent greater than the number carried out in January 2018 with over 25 million search results presented in March 2019 (Wales Audit Office, 2019). Carers using the site have reported easy access to this web page information (Care and Social Services Inspectorate Wales, 2017).

However, the website can only be as good as the quality of the data and information it contains and the approach of local editors to maintaining and checking entries varies with records not always being kept up to date (Care Inspectorate Wales, 2020). Due to the number of poor-quality entries, some third sector bodies were found not to value Dewis Cymru (Wales Audit Office, 2019). The increase in searches suggests the website has potential to be a central source of relevant and up-to-date information. The Welsh Audit

Office recommend a full evaluation of the role of Dewis Cymru in the wider implementation of the Act and the data gained used to build on its potential as a national information-sharing portal. (Welsh Audit Office, 2019)

Carer groups

Prior to the pandemic, carer group meetings were valued and felt to be a good source of information and support providing good company, a place to meet people and share concerns and positive experiences (Care and Social Services Inspectorate Wales, 2017). Some counties had regular carer information days and carers told about the warm human response they receive along with information leaflets and contact details of support groups and services available to carers.

> *'I went to the GP with my mam and saw the carers centre banner. I wasn't going to do anything about it, but this was on one of mam's good days, which she asked about the banner and was told someone from [organisation] was there is they wanted to talk. I felt this is going to be another false promise. I was too scared to hope, but when we went into the room I recognised the lady. Also was good as it's the person who runs the project I would then end up accessing…There was support there if needed. It was a chance for respite and take mind off things.'*

(Iredale, 2020, pp31)

Role of third sector

Linked to access to IAA, but cutting across all of the enablers, is the role of the third sector. The health and social care system in Wales is more than just NHS services and local authorities, it includes the third sector, particularly their crucial role in supporting carers. The third sector provides a range of advice, information and support to carers that are specific to their individual needs (Welsh NHS Confederation, 2018; Social Care Wales, 2017; Carers Trust Wales, 2019).

The important role of third sector organisations in helping provide and share information was evidenced in Track the Act Briefing 5 (Carers Wales, 2020a). Those who had received information from any source were asked if they found the information provided helpful or useful. On average 71 per cent of carers found the information useful but there were distinct differences in the satisfaction levels depending on who provided the information (Carers Wales, 2020a):

- Carer charities and disability charities were considered the best for providing information with an 85 per cent satisfaction rating.
- 75 per cent of respondents said that local authority information was useful or helpful.
- Those accessing information through the NHS were less satisfied with the information provided, with only 54 per cent saying that it was useful or helpful.

The Measuring the Mountain stories highlighted a particularly valuable role third sector services are providing for adults in transition from youth to adult services (young adults). As discussed in the **Measuring the Mountain** section (pp7), participants are not specifically asked about assessments. However, the quotes below highlight the role of young adult carers services in signposting to support, helping young carers recognise their caring role and providing somewhere or someone they feel comfortable talking to.

Access to IAA for young adult carers: Measuring the Mountain stories (2020)

'Before I found out about the Young Adult Carers project I had no support around my caring role for my mum and was trying to juggle this with university and being a single parent for my six-month old son. Since their support I have had regular home visits and 1:1s with my key worker, been signposted and referred to other agencies for support around benefits advice etc.'

"It was really, really tough and hard, before I got support from the Young Adult Carers Project at the carers centre. Nan found out information for her which lead to me getting support. The GP told me about being a carer − what support and I filled in a form which was sent to the carers centre. I dunno what I'd do if I didn't have support − likely still be struggling. I would likely still be looking if I didn't already know about it (support). It was a weight lifted off my shoulders, that I could talk to someone, means less pressure on my family. Was good to finally talking about it (caring role and my granddad passing away). It's really helped me no feel alone and get support, just to talk. I feel I got the right information and the right time, I have had support I needed when I needed it and support not just linked to my nan, general support too.'

'… What I like about the Young Adult Carers project is that they support you no matter what, even if a caring role ends. One day I knew the youth club was happening and I just turned up as did not want to set expectations that I would attend. It has taken me a long time to realise I do need support and I need to stop being isolated. I tried accessing other services that I thought would help, but they palmed me off or didn't have the right thing for me…Lots of professionals don't take me seriously but [name] who runs the YAC (Young Adult Carers) project does. I am always taken seriously and never forgotten…'

Responses to the Consultation on a carers' national plan for Wales also recognised the value of third sector organisations working alongside local authorities to provide information during the pandemic. Third sector organisations reviewed official guidance from Welsh Government, Public Health Wales and others, turning it into shorter and more easily understood information for carers and service users. In this way they ensured the most essential information was shared (Welsh Government, 2021a).

When thinking about feelings of stigma or concerns around involving social services, the third sector can play a role in signposting and supporting people that may be less likely to approach public sector bodies. North East Wales Carers Information Service (NEWCIS) has adopted a service whereby third sector staff have been trained and enabled to carry out carers' needs assessments. This has resulted in carers who may feel inhibited from having honest conversations with a social worker, for a variety of reasons, having a choice as to who completes their assessment. A further benefit is that each carer assessment worker is given up to eight hours to complete an assessment (Welsh Audit Office, 2019).

Having someone to talk to and ask questions: Measuring the Mountain stories (2020)

'The carers centre is fantastic as there's always someone there to get in touch with − they helped with benefits, give out foodbank vouchers, out of this world.'

'If it wasn't for the voluntary group I have recently joined I don't know what I would have done, just knowing what other people have been through is helpful and because many have similar experiences to share I am getting the advice I need.'

> *'I met [name] who runs the Young Adult Carers project and had a long chat about what was going on for me. I felt we had been friends for years but only just met. She referred to lots of people for additional support...Her and the project has made a positive difference to me and I have had consistent reliable support.'*

Third sector bodies themselves have indicated that they could further contribute to IAA and address some of the current gaps in services, but that they face some barriers to doing so including not being consulted on the practicalities of new services they are asked to provide or being given additional funding to do so (Wales Audit Office, 2019). Further concerns have been raised over the sustainability of third sector support that receives short-term grant funding (Social Care Wales, 2017; Carers Trust Wales, 2019; Care and Social Services Inspectorate Wales, 2017; National Assembly for Wales, 2019).

Advocacy

Advocacy means giving a person support to have their voice heard and can involve helping them understand their rights as well as express their views. Carers are often advocates for the people they care for, but young carers and some adult carers may benefit from forms of advocacy. Advocates may help with the identification of carers and support them with the assessment process and the need for more to be done to support carers through advocacy has been recognised by the Welsh Government (Welsh Government, 2020c).

The Care and Social Services Inspectorate Wales (2017) identified some examples of advocacy-type services or job roles that help identify or support carers:

- New community wellbeing coordinators were identified as a positive move for some local authorities.
- The presence of a 'carers champion' in social work teams, education and health can be effective in raising awareness, although current practice was found to be inconsistent.
- For those caring for people with mental health needs or substance misuse issues, access to support was thought to be easier where a care coordinator was already allocated to the person with mental health needs.

A small number of respondents to the Consultation on a carers' national plan for Wales mentioned access to advocacy services, commenting that it is important in many situations both for older carers and young carers and can help carers access information, help those who find it hard to access services, and/or find it difficult to talk about their problems (Welsh Government, 2021a). The Welsh Audit Office found that only a quarter of carers surveyed in The 'front door' to adult social care (Welsh Audit Office, 2019) stated that they had been offered advocacy services.

As example of advocacy is the Gwent Regional Partnership Boar, who with Aneurin Bevan University Health Board are supporting Blaenau Gwent with a 'compassionate communities' pilot to support carers and are developing a regional advocacy service. Intermediate Care Fund (ICF) funding in Gwent is intended to develop a carers' hub across the region with satellite centres in the Vale of Glamorgan, and a team around the individual for anyone with a diagnosis of dementia. The ambition is to support carers by navigating services and systems for them (Care Inspectorate Wales, 2020).

For **young carers**, advocacy may occur in educational settings. Where secondary schools, colleges and PRUs have a lead member of staff for young carers, identified young carers feel confident and able to raise concerns. Part of this role is to champion their rights and liaise sensitively with parents and other professionals (Estyn, 2019). This approach supports more consistent identification and signposting for young carers.

Diverse and flexible provision of support

As highlighted in the **Mismatch between expectation and outcomes** section (pp21), previous negative experiences of assessments and their outcomes could act as a barrier to seeking support again. Whilst this review is not about the provision of services, there were a few key points from responses to the Consultation on a carers' national plan for Wales (Welsh Government, 2021a) that indicate enablers to accessing assessment and having a positive experience:

- The critical importance of ensuring more young carers can access respite and have a break from caring was highlighted in the recent consultation responses, as well as the importance of respite being timely and appropriate with a choice of different forms of respite (Welsh Government, 2021a).
- Direct Payments (DP) were addressed by several replies, with support for more creative uses of these to ensure they have an impact on improving the resilience and wellbeing of carers. There were a number of comments from individual carers that local authorities do not understand DPs and their more innovative use should be encouraged. However, there should be clarity between the users of DPs, with a comment made that these are awarded as the result of a needs assessment for a cared-for person, not the carer (Welsh Government, 2021a).
- When asked in the consultation '*Is there anything more we should do to support life alongside caring?', r*esponses highlighted the need for more flexibility (Welsh Government, 2021a)

These comments echo the findings of the Care and Social Services Inspectorate Wales report (2017) which emphasises the need for local authorities and the commissioned carers services to demonstrate flexibility and innovation in responding to what matters to carers. Social Care Wales (2017) highlight that there are areas of good practice including regions that are mapping and exploring more flexible options to meet the needs of particular groups, such as those with autism or dementia.

Well trained frontline staff and the sharing of best practice

The first step in delivering appropriate support always starts with individuals and professionals being equipped with the information and tools they need to identify carers and to understand the barriers they face (Welsh NHS Confederation, 2018). Across the positive stories recorded in the Measuring the Mountain data were examples of professionals from within social care, healthcare and the third sector who delivered excellent support, responding specifically to the needs and wants of the individual they were working with (Iredale, 2020). Positive experiences have been shown to build trust in service providers. These experiences were often seen to lead to contact and communication that was immediately preventative and facilitated the provision of ongoing support if needed (Iredale, 2020).

Some social care staff and other practitioners may be reluctant to promote access to assessments due to what Seddon and Robinson (2015; cited in Henwood, Larkin and Milne,

2017) termed 'practitioner ambivalence'. This occurs when practitioners perceive that there's a lack of new types of support for carers and have concerns around raising carers' expectations when they do not feel the services available can address their needs. This may be particularly so for the emotional and relational challenges of caring. While this was not research in the Welsh context, practitioner ambivalence could be a useful concept to consider in relation to training and supporting frontline staff.

Linked to well trained staff, is the sharing of best practice across local authorities, sectors and organisations. This involves the collation, sharing and learning of good practice and requires structures to be in place to do so, in addition to team-based learning (Welsh NHS Confederation, 2018).

> *'There is no clear evidence to suggest which model of support is most effective and given the difference in services and geography it is not clear that direct comparison would be possible or even desirable. For example, some local authorities commission third sector organisations to carry out carers needs assessments and provide support; others directly employ carers officers. Where local authorities directly consult, engage and commission with a number of third sector organisations to deliver support to carers, the coordination of events, information and the delivery of updates is more focused and targeted, and evidence that outcomes for carers are improved is clear.'*

(Care and Social Services Inspectorate Wales, 2017 pp8)

COVID-19

Most of the evidence and data used in this review predates the COVID-19 pandemic. There are a number of sources that are about, or include information from the pandemic. None of these are specifically about assessments, but there is some relevant information within them.

- **Impact on Unpaid Carers in Wales** (Carers Wales, 2020c)
- **The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak** Carers Week 2020 Research Report (Carers UK, 2020a)
- **Caring behind closed doors: six months on** (Carers UK, 2020b)
- **Summary of responses to Consultation on a carers' national plan for Wales** (Welsh Government, 2021)

Key statistics relating to carers during COVID-19: Behind closed doors (Carers UK, 2020b)

- The number of carers in Wales is estimated to have grown from 370,000 to as many as 683,000
- Four in five (80 per cent) of carers report that they are providing more care now than before the pandemic began
- More than three quarters (76 per cent) say the person they care for needs more support since the pandemic began
- More than three quarters (76 per cent) are reporting to be exhausted and worn out by their caring role during the pandemic

- More than a quarter (29 per cent) are struggling to make ends meet due to the extra financial pressure of the pandemic

Awareness of unpaid carers is higher in the UK since the outbreak of COVID-19. In a survey of the general public in May 2020, 48 per cent of those who had never been a carer said they were either more or much more aware of unpaid carers (Carers UK, 2020a). It is not yet known if this awareness will translate into increased identification of carers.

A key finding of the Carers Wales (2020c) report was that **many carers found it difficult to speak to anyone about their situation.** The ability of local authorities to provide information, advice and needs assessment during lockdown was severely impacted. Partly, this was because many carers teams in local authorities were redeployed to other areas of activity.

The report highlights that carers found that they were unable to access assessments despite the often huge change in their caring responsibilities. **The person-centred approach outlined in the Act was forgotten**, and carers were expected to fit in to any surviving support. In October 2020, Carers UK called for the Welsh Government to *'reinstate as a matter of urgency its commitment to an awareness raising publicity campaign to identify and inform carers of their rights'.* (Carers UK, 2020b, pp29)

Communication methods changed, with remote delivery of 'what matters' conversations and carers' needs assessments (Carers Wales, 2020c).

A number of examples of carers gateways, community hubs and emergency carer packages are highlighted in the Carers Wales report (2020c), although it is not clear from the perspective of carers how well these worked.

The responses to the Welsh Government's Consultation on a carers national plan for Wales (2021) included the question, '*Do you have examples of good practice during the pandemic that could be replicated or inform development of services*?' There were 55 responses to this question and some of the most pertinent findings are:

- A number of carers described positive experiences of someone making the effort to directly contact them to offer support or help. This could be a social worker, care workers, healthcare staff, GP or others. Whilst it is not clear if these were assessments, carers reported being asked how they were, if they needed help, for example, with shopping, or having someone on the phone to listen.
- Feedback from those working with young carers found that regular telephone calls made a difference, enabling the carer to feel connected and for professionals to respond and address any issues quickly.
- Public sector organisations reported benefits to establishing closer working relationships with a wide range of different organisations, including their commissioned carers' service providers.
- Coordination with voluntary sector-led response services and third sector partners was highlighted as an example of improving support for carers, by linking statutory services with organisations delivering different forms of support in the community.
- Some organisations ensured their staff had more and better knowledge of the range of support available for carers. For example, access to the carer contacts directory of

information, systems for carers to obtain PPE and to access COVID-19 tests, and teams providing food parcels for carers living in poverty.

- Information and advice were circulated to carers, for example, updated carers' handbooks and guides, links for accurate COVID-19 advice, and tips on maintaining mental wellbeing.

The experiences of different carer groups (e.g. young carers, carers for older adults with dementia) is likely to have varied greatly with some groups also having been at much higher risk of serious ill health or mortality due to COVID-19 (Black, Asian and minority ethnic groups, people living with dementia). To date, there is a lack of published information regarding what has and has not worked well in relation to 'what matters' conversations and to carers' needs assessments during the pandemic for different groups.

It is likely that some best practice will continue into the future, including the rapid increase in online service provision and remote methods of communication where that is preferred. The evidence that was reviewed and published to date does not provide insight into which services and structures worked best for carers.

Experiences of carers' needs assessments

In their survey of 550 carers, the Wales Audit Office (2019) found that just over half of carers (54 per cent) access an assessment following a professional's referral (social worker, hospital, nurse, GP or health worker, for example) of those the majority (69 per cent) said that it was made clear that they were being assessed as a carer. However, just over half of carers (54 per cent) were satisfied with the outcome of their assessment, and only 44 per cent stated that they were provided with a written copy of the agreed outcomes of their assessment.

This section considers the available information on people's experiences of the actual assessment, both positive and negative. The evidence is arranged into four key themes:

- Knowledge and attitudes of professionals
- Feeling heard and being treated with respect
- Need for flexible support that is carer centred
- Pressure of time and resources

Knowledge and attitude of professionals

As outlined in Part 3 of the Code of Practice (Welsh Government 2015), all practitioners undertaking assessments must be suitably skilled, trained and qualified in undertaking assessments. A local authority will also need to be satisfied that all staff undertaking these activities have the skills, knowledge, and competence to work with children and young people, adults and carers, as appropriate (Welsh Government, 2015).

The knowledge and attitude of Social Services staff has been found to have a significant bearing on assessment access and process (National Assembly for Wales, 2019).

Measuring the Mountain stories (2020)

'I was having a carers' assessment. The social worker who came to the assessment phrased all the questions really negatively…Needless to say, the assessment didn't go well and she didn't offer me any useful support, I ended up referring myself to other forms of support."'

'My experience of being the carer of my son who has complex needs has been horrendous. Since day one when he was diagnosed in 2003 there has been very little support instead bullying, unprofessional behaviour from Social Services, some lea (local education authority) staff, NHS staff, cover-ups, neglect of care and still no correct care identified in high court as needed in place.'

Responses to the recent Consultation for a carers' national plan for Wales (Welsh Government, 2021a) included a number of suggestions to improve the approach and knowledge of professionals undertaking assessment:

- The importance of local authority staff being trained in undertaking formal carers' needs assessments for young carers, as well as ensuring they are carried out in an age-appropriate way.
- The terminology, language, purpose and outcomes identified during an assessment was raised as being very important. The use of different words or phrases by local authority social care staff may cause confusion amongst carers. A softer, less formal approach when carrying out an assessment could be easier for a carer to have that important conversation about their support needs. Simple and easy-to-understand language was therefore needed.
- There was a suggestion, that because of the frequent link between caring and low incomes, the carers' needs assessment should include a right to be referred for a benefits check. This is something the person doing the assessment would need to know about.

Feeling heard and being treated with respect

'Listening can build trust, increases disclosure, reduces defensive behaviour and decrease "hidden harm" because it potentially keeps the door ajar to the carer/family which might otherwise remain shut.' (IPC and SC Wales, 2019a pp48)

Carers emphasise the importance of feeling heard and of being treated with respect when trying to access and also during a carers' needs assessment (or a 'what matters' conversations) (Social Care Wales, 2017). Whilst these are quite broad terms, there were a number of themes within them.

Carers report that they want to have their stories heard and hold meaningful 'what matters' conversations with social workers, which are then responded to (Care and Social Services Inspectorate Wales, 2017). In practical terms, **carers look for a feedback from the assessor that they have been heard** – at the time and in any reports or outcomes from the assessment or conversation.

> *'You know that you have been listened to when people repeat back to you what has been said – this helps to ensure that their understanding is correct.'*

(IPC and SC Wales, 2019a)

Cooke et al, (2019) analysed Measuring the Mountain stories and found that positive experiences of accessing support had included **shared decision-making power,** good communication and flexible approaches by social care professionals. Conversely, negative examples involved social care staff being the 'primary influencer' (pp78). These stories demonstrated how important a carer's relationship with social care professionals could be and how much carers valued people who listened, treated them with respect and believed what they say.

Some carers felt the assessor had 'made up their mind' beforehand, an impression they had either during or after the assessment.

Feeling unheard: IPC and SC Wales (2019a, pp49)

'You often don't know if you have been listened to until you push the point then discover that you haven't been listened to at all. Sometimes, you might not realise this until you have received a copy of the typed-up assessment afterwards.'

'Professionals sometimes give the impression they have already made their mind up and they know best. Listen to the carer and keep an open mind.'

'I know I wasn't being listened to by the providers for my Nana because they kept saying the same thing back to me and they were being defensive when I had other ideas.

The manner in which these conversations take place and the outcomes as a result are of great importance. An appropriate space which **feels safe and allows for privacy** is vital. Measuring the Mountain stories (2020) demonstrated that a lack of privacy and not feeling heard were significant barriers, but 'getting it right' was a key enabler. Additionally, carers did not feel they could be as honest as they would have liked when assessed in front of the person they cared for (National Assembly for Wales, 2019). In contrast, **by providing a safe place and situation for people to talk, barriers created by past negative experience could start to be taken down.**

Positive environments for conversations and assessments: Measuring the Mountain stories (2020)

'His reviews happen at the day centre and the staff sit it in while they're happening. They're privy to all these discussions so you can't talk freely. They were asking me about my finances as I was struggling but I didn't want to say that in front of anyone.'

'The JCP who I was with before moving was hell as it was too busy and you know everyone there. I didn't feel safe. I then went to Gorseinon one where it was small and quiet and staff really nice including security bloke. I hate waiting due to anxiety but always got seen straight away. We had long chats with me and the job coach. She actually listened. She said "how are you doin?" then I wombled off what I do in the day. I was then told to access the carers centre. The work coach in the JCP was really supportive. She gave me information and advice I needed without being overwhelmed or pushy.'

'I was too scared to hope, but when we went into the room I recognised the lady... She was asking all the right questions.... But from me being let down so many times, it was self-defence mechanism to take what said as a grain of salt. I was encouraged to access the project and the youth club that's run for Young Adult Carers (YACs). I actually backed away a few times from coming to the YAC youth club, but felt this may work.'

'I met [name] who runs the Young Adult Carers project and had a long chat about what was going on for me. I felt we had been friends for years but only just met. She referred to lots of people for additional support...Her and the project has made a positive difference to me and I have had consistent reliable support.'

'Thankfully we had an amazing social worker in the Adult Learning Disabilities team, who was able to get the ball rolling so that I was able to become my brother's PA.'

The converse of feeling heard, are reports of people *'feeling judged, or being made to feel guilty for asking for help, or… being made to feel unworthy or a failure'* (Cooke et al, 2019, pp33). These negative experiences could occur either when initially seeking help, or later during assessment or the provision of support. Given that feelings of stigma and shame are key barriers to seeking support, these types of experiences seem likely to compound this.

Carers additionally report that the assessment process can be useful in itself as it can **provide an impartial overview** of their caring situation. This reflection can help provide the carer with greater awareness of their situation as well as other approaches, help and support (Carers Wales, 2020a). This more therapeutic value of carers' needs assessments could be further explored (Care Inspectorate Wales, 2020)

Need for flexible support that is carer centred

The training manual provided by Institute for Public Care and Social Care Wales states that a carers' needs assessment is 'is NOT a gateway to a fixed menu of services or a gateway to "no further action"' (NFA) (ICP and SC Wales, 2019, pp27). However, carers report a lack of flexibility around support being offered or a lack of suitable support (Care Inspectorate Wales, 2020). This included challenges around planning and preparing for future events.

Need for carer-centred support: Measuring the Mountain stories (2020)

'I care for my husband. I'm going to get my shoulder operated on. I got in contact with Social Services about organising personal care for myself − I won't be able to change the dressing and things by myself and my husband won't be able to help. I was told that I'll have to wait and see, that it will be sorted out after the operation. I'd prefer to prepare though and know that everything was in place. The nurses I spoke to at the pre-op didn't know and said we'd have to wait and see.'

'The only respite on the island is emergency and would mean him going somewhere unfamiliar which he would hate. I needed to have an operation on my knee and wouldn't have felt okay with that if he'd been in this respite so he went to stay with [name].'

'My husband has Huntington's disease and I care for him − we have support with this too. I would like to get some respite plans in place in anticipation of his condition getting worse and me needing more of a break. When I've enquired about this, the conversations I've had have been really confusing, it seems I have to wait until I need the respite before I can get the information I need but I'd prefer to know about options, how it works etc. ahead of that. I've been told to look into Direct Payments but I don't really know what these are and my husband's needs are all classed as health care...'

A lack of sufficient age-appropriate support for carers with services too often focused on adults has also been identified (Welsh Government, 2021).

Seddon and Robinson (2015) highlighted deficits in the conduct of carer assessment such as reliance on structured problem-focused assessment protocols that restrict discussions and **fail to capture the complexity of carers' lives**, **hindering the hearing of the carers' voice**, and **failing to capture the reciprocal nature** of caring relationships (cited in Welsh Government, 2020b).

When carers do not get access to the things that they state will help, their wellbeing and ability to cope is undermined (Care Inspectorate Wales, 2020). Therefore, the carers' needs assessment '*must consider the outcomes the carer wishes to achieve for themselves*' (ICP and SC Wales 2019a, pp19). The ability or willingness of a carer to continue in their role should be examined and not assumed. Some carers feel the expectation that they will continue to provide care is a heavy burden they are obliged to carry, or is assumed they will carry. Others felt caring had become a duty, a burden they felt unable to relinquish, as support was not available from elsewhere (Care Inspectorate Wales, 2020)

> *'My wife's illness has completely changed my life, I can't do the things I want to do. I want my life back… I was offered a sitting service to give me the opportunity to attend a coffee morning, I don't want to go to a coffee morning and I've never liked coffee, I want to get on with my life; there are no plans in place for if I should stop caring.'*

(Care Inspectorate Wales, 2020, pp16)

Care Inspectorate Wales recognises that the right to assessment granted to carers in the 2014 Act, is yet to achieve its ambition of promoting the wellbeing of carers in a way that acknowledges and responds to the scale of change some people face when they become carers (Care Inspectorate Wales, 2020).

> *'There are important issues for carers around what will happen to the cared-for person when they are no longer able to care for them. This needs consideration.'*

(National Assembly for Wales, 2019, pp21)

Relating back to the section on the mismatch between expectations and outcomes, some carers report a positive assessment experience, which appeared to be helpful at the time, but which later turned out not to have helped in the way they had hoped.

Positive assessment experiences with an unsatisfactory outcome

'I had a carers' assessment a little while ago − the person who did it was very nice, said lots of things and asked questions, but none of it was relevant.' (Iredale and Cooke, 2020, pp46)

'We were treated with respect and it was very helpful, but I still don't have the help which was recommended. I was also given two more weeks of respite care to be taken before the end of March, but the local council care home is full until next June and I can't find a private one who can help.' (Carers Wales, 2020a, pp14)

Carers for people with mental health needs or substance misuse issues reported that even where they had received a carers' needs assessment, it was rarely updated or reviewed and there was a lack of specialist support available that was locally accessible (Care and Social Services Inspectorate Wales, 2017). Some carers feel that social services staff offer support in accordance with the resources they have to work with rather than the individual need of the carer (National Assembly for Wales, 2019).

Related to the need for services to be carer centred is the need for **co-operation and partnership working between different agencies**, including local authorities, health boards, third sector organisations and education providers (Social Care wales, 2017). From the perspective of the carer and the person being supported, it can feel like being ‘bounced’ from service to service, rather than the person’s needs being placed at the centre and them being guided through the system. Integrated support can promote person centred care, improve outcomes and enhance wellbeing, especially for those with the most complex needs (Social Care Wales, 2017).

Pressure of time and resources

Despite developments in funding (Carers Wales, 2020b) evidence suggests that statutory providers are under pressure due to reduced budget (National Assembly for Wales, 2019) and social care professionals are under pressure both in terms of case load and resources (Carers Wales, 2020a; Care Inspectorate Wales, 2020). One practitioner reports of a ‘*relentless pace of referral, lack of resources and competing demands*’ (Care Inspectorate Wales, 2020, pp17). Not being able to offer people the care and support they knew they needed resulted in some practitioners feeling they were letting people down (Care Inspectorate Wales, 2020).

This pressure on professionals and stretch on resources is also evidenced in Measuring the Mountain stories (2020), with some carers reporting feeling under pressure to make big decisions very quickly.

Time pressure and lack of resources: Measuring the Mountain stories (2020)

‘Being a carer. Two years ago my nana was diagnosed with mix dementia and moved in with me October 2017. Had a lot of interaction with social services. One time back in May 2019 my nana was taken into hospital with cancer, I received a telephone call from social services (social worker) to invite for a meeting following Monday. Were not given any information about what the meeting entailed. At the meeting there was family (me and mum primary carers) social worker and a nurse. We were asked what we would like to do next, the meeting was let morning around 11am. Social worker expressed that she was going on leave and would need an answer by lunch-time. Pressured family into making a decision on life-changing caring responsibilities (care home), pushed the option of going in to a home and was offering no alternatives, with limited options of places to go. The social worker pushed certain homes, respondent felt the social worker was bias to services and gave limited information. She explained while she was away there was no one to take on her work load and used the phase 'if you don't make a choice today your nana will die in hospital'.’

’I was told I couldn’t have a carers’ assessment because of the needs of my child. I spoke to someone from the local learning difficulties team and because they pushed and pushed for months for it, I have, finally just had a carers’ assessment. The person who did it told me that she sees I have needs but that her team (she’s part of children’s intake) could not meet those. This has been reported but nothing has happened. There’s no funding anywhere for this group of children or for those that support and care for them so no one would look at any of it.’

’I feel like I’m being greedy because I ask for things that are needed, things that are mandated. I said that carers’ needs assessments are a duty – they say they don’t have the resources. They try to stop the Act happening – they don’t offer assessments…’

If resources are not available to provide the support needs identified in a carers' needs assessment, the process itself can feel meaningless (National Assembly for Wales, 2019). This has a negative impact on the assessment process for both carers and professionals.

> *'Nothing happens after an assessment now – but how could it without the money?'*
> **Participant from Carers Wales Committee (National Assembly for Wales, 2019, pp84)**

Linked to this feeling of a lack of resources, was the experience of carers who felt they constantly had to battle or struggle for services (Iredale, 2020). In this context, access to and experiences of carers' needs assessments are part of this much wider system which carers are aware has limited resources and can also find challenging to navigate.

This is clearly summarised by Cooke et al, in their 2019 report based on earlier Measuring the Mountain data: *'In these cases, interactions with social care providers are characterised by difficulty, delays, frustration and confusion. Many of the examples shared relate to the systems and processes that govern social care provision and which frequently appear to add, rather than remove, obstacles to good support.'* (pp.33)

These experiences of the pressure on time and resources and navigation of the wider system relate back to the barriers outlines in the **Mismatch between expectations and outcomes** section (pp21).

Gaps in our knowledge

This review has highlighted a number of evidence gaps.

Young carers

There was considerably less information in relation to young carers than to adults. A number of key sets of evidence, including local authority data and carers surveys, do not include data on people under 18.

In 2019 Estyn highlighted that there was a lack of reliable data on young carers and how many there are in schools, colleges and pupil referral units (PRUs) across Wales. They recommended that the Welsh Government should produce reliable, nationally-collected data to help identify young carers.

As such, it is still not clear what a carers' needs assessment is like for young carers or how this has changed during the pandemic, particularly given the impact on education and the role that could play in the identification and support of young carers.

Consideration should be given to a separate study or information gathering exercise specifically for young carers (and young adult carers in transition), as the 'mainstream' information does not include enough information and it could also be that schools and other services have information that would be helpful.

Generalisations and complex contexts

There are a number of gaps in context-specific information that may make it hard for high-level findings to have an impact 'on the ground'.

The **frontline identification of carers** and delivery of carers’ needs assessments appears to be hit and miss, between and within local authorities and can depend on the professionals involved. As such it is hard to know which professional groups, roles or possibly individuals should be targeted in increased training about and awareness of carers.

There is not enough information on some ‘hard to reach’ groups, including Black, Asian and minority ethnic groups and LGBTQ+ carers, confirming similar observations by Henwood, Larkin and Milne (2017). As such, it is hard to know what the specific needs of these groups, if they are being met and, if not, how they could be supported.

This review has not looked at **combined assessments** for the person being cared for and the carer, either since 2016 or during the pandemic. More information on this may be helpful, including learning around remote communication and assessments when it may be hard for the carer to be in another place/room to the person they care for during lockdown.

The role of the **third sector** during the pandemic and positive models for the future would be valuable to both local authorities/commissioners and those using services. The role of the third sector in assessments specifically as opposed to service provision more generally could not be determined from the evidence.

Track the Act Briefing 5 (Carers Wales, 2020a) highlights that in general the number of carers’ needs assessments are down with some reporting less than half than the year before. There are anomalies though, for example Newport local authority reported a 1,500 per cent increase (71 to 1,136). The reasons for this are hard to untangle given the problem highlighted in the **Confusion over terminology** section (pp19), but in could be that some in-depth case studies into some local authorities may be helpful.

COVID-19 data gaps

In general, COVID-19 creates a significant research and information challenge as the impact of the 2014 Act can be tracked for four years and then there is a huge societal change that will continue for some time and many aspects of supporting people who use services and their carers will not return to as they previously were. Unpicking those pre-COVID-19 findings that are still most salient is a complex task. It will be important to understand the perspectives of both carers and professionals, as it is very possible that their understandings and priorities will diverge in ways that differ to prior to the pandemic. Moreover, the changing landscape for any evidence and research means some information goes out of date rapidly.

Co-production of services and of individual support/provision and person-centred support more generally has suffered during the pandemic. Information is mainly from 2020, but in such a fast-changing COVID-19 and policy landscape, identifying where this is now being started/restarted and is going well, would be a helpful area of knowledge.

There exists a discrepancy between the number of carers (which has risen sharply during COVID-19), how important they are within society, and the high numbers that do not meet the criteria for support. Understanding this discrepancy may help both carers and frontline staff understand the landscape and system.

It will be essential to understand pathways/journeys through the system, including assessments. Currently, many stories are a snapshot that lacks wider context. The review highlights that previous experiences and expectation of carers play a significant role as an enabler or barrier to assessments. This is an understandably complex task however, given the range of pathways within and between local authorities.

Conclusions

A key finding of this review is that most of the literature and evidence in relation to carers' needs assessments relates to adults rather than young carers. Additionally, there is little evidence in relation to COVID-19 and assessment processes, but rather more general information about support for carers. This also relates to limited information on different groups (e.g. caring for an older adult with dementia or an adult with a learning disability or a child with a disability) specifically in relation to assessments.

The impact of COVID-19 on services and research poses a significant challenge for understanding what worked well and what lessons and interventions should continue into the future. During the pandemic there has been less co-production of services, individual support plans and of research/evidence. There is an opportunity for carers to play a key role in shaping both the future evidence base and assessment processes.

Many carers and professionals still do not know or fully understand the rights of carers to have an assessment or what the outcomes of such an assessment could be. This additionally relates to confusion around terminology, especially regarding 'what matters' conversations and carers' needs assessments.

This review has focused on carers' needs assessments, which are just one part of a wider system to support carers. However, it is not possible to entirely separate out the support provided from the assessment process and how this is perceived by both carers and professionals. Where people are not eligible for support, that support is inflexible or they feel the assessment outcome was decided before it started, they will be less likely to seek assessment in future. Managing expectations is important so that carers understand what services may be available or what the outcomes of an assessment could be (including not being eligible for support at that current time). If carers see no obvious benefit to assessments however, they will not seek them out for an initial or re-assessment.

There are positive examples of assessment and contact with professionals both before and during COVID-19 where carers have felt listened to, respected and supported. In some cases, people with very low expectations of an assessment or with a poor previous experience of the process were reassured. The assessment process in itself can be a positive experience and offer people options they had not previously thought of, even if they are not eligible for a particular service.

It is clear from this review that there is considerable consensus in the literature about some of the barriers and enablers of accessing assessments or wider support, but less consensus about successful interventions and approaches, especially during the pandemic. Many of the barriers and enablers identified would be relevant across groups, but further work is needed to understand some of the specific challenges that some groups are experiencing.

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Appendix: Overview of the Measuring the Mountain stories

Table 1: Barriers to accessing an assessment/support

Theme	Number of comments (Total 109)
Lack of clarity or information about how to access support/unsure that support would help	26
Professionals missing the opportunity to refer on/being hard to contact	22
Loss of referrals/lack of follow-up	17
Feeling previously let down by services	15
Wanting to be independent/finding it difficult to ask for help	7
Not meeting criteria	7
Not identifying or being identified as a carer	6
Person being cared for not wanting additional support	3
Stigma of involving social services/unsure of what involvement would mean	3
Lack of suitable support/provision locally	3

Table 2: Enablers to accessing an assessment/support

Theme	Number of comments (Total 40)
Initiative of professionals in raising awareness of support/being already known by professionals	16 GP=5, Teacher = 2; Social worker = 2; YAC = 2; Local LD team = 1; Mental health nurse = 1; Team around the family (TAF) = 1; Job Centre Plus (JCP) = 1; Not identified = 2
Being taken seriously/approach of professionals	12
Recognising oneself as a carer/ as needing support	5
Peer advice/voluntary organisations	5
Reassurance and explanation of what will happen by professionals	2

Table 3: Negative experiences of assessment

Theme	Number of comments (Total 39)
Change in criteria/re-assessment resulting in sudden changes to provision	7
Perceived pressure on resources and time	6
Assessment not addressing all needs	6
Carers' allowance is not sufficient	3
Manner/approach of the assessor	3
Delay in accessing assessment or response to assessment recommendations	3
Difficulties in planning for future events	3
Carers' allowance being withdrawn due to clash with another payment (e.g. pension or maternity)	2
Feeling under pressure to make decisions quickly	2
Lack of choice as to how payments are made	2
Lack of continuity of staff	1
Lack of privacy to discuss details of assessment	1

Table 4: Positive experiences of assessment

Theme	Number of Comments (Total 12)
Appropriate information and service	4
Funding for specific needs	3
Signposted and referred to other agencies	2
Attitude/manner of professional	1
Ongoing support when the person being cared for moves out/dies	1
Security of knowing funding will be there	1

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