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Arolygiaeth Gofal a Gwasanaethau Cymdeithasol Cymru
Care and Social Services Inspectorate Wales

# In support of *carers*

## Carers engagement overview report

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Mae'r ddogfen yma hefyd ar gael yn Gymraeg.
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# Foreword

**By Sheila Meadows, member of CSSIW National Advisory Board and chair of Ein Llais North**

Most people at some time in their lives will become a carer for a family member, it is not something we plan for or a role we actively seek, but we become a carer because we love the person and want to help them as much as we can. In my lifetime society has changed hugely and families are more scattered and often smaller, the population is getting older and with most women working the caring role, when it comes, can pose a real struggle for many families.

The Social Services and Well-Being Act (SSWBA) recognised the pressures caring puts on individuals and families and has hopefully begun a societal change to both recognise the vital economic contribution of family carers and puts pressure on local authorities to consider and meet their needs, not as an afterthought but as a right. It is really important that elected members of local authorities fulfil their role in upholding the spirit of this Act, treating carers as equal partners in the role they undertake and make information and support available to them as a right, not just when a family is in crisis which has traditionally been the case.

As a parent of a severely disabled son I have been a carer for many years and will continue to care for the rest of my life. I have cared for elderly parents, and other elderly family members till their death. I am no saint, it just happened that I took on the role but as I reached retirement age, I was forced to look for support for my son who needed more stimulation and care than I had the energy to offer on a daily basis. But why, 10 years on, do I still feel guilty about having to take that step, having to admit that I was no longer coping as I had before.

The SSWBA hopefully will support carers earlier, will do what is right for people who need greater care and support than a family member can give. Carers need to feel secure in sharing the care of their family member, there needs to be a partnership approach ensuring the best outcome in life possible for those being cared for is achieved, thus giving me and many like me, the chance to be a proper Mum or Gran or daughter.

In my role as Chair of the Ein Llais, North Wales group I will raise the question many times “Are Carers receiving the support they deserve? If not why not?” CSSIW inspectors, through their inspections must ensure that not only are the services people receive of high quality, but that the ethos of the SSWBA as it relates to carers is upheld. CSSIW will need to work closely with Directors of Social Services and lead council officers to raise the profile of carers rights, to ensure they understand the hugely demanding and valuable role carers provide in today’s world and support them as is their right when they need that support.

# Summary

- In transforming services in line with the Social Services and Well-being Act, support for carers has not been at the forefront of planning and delivery for local authorities and their partners.
- Most local authorities have carers strategies in place but some of these have not been reviewed to reflect changes under the SSWBA.
- There are examples of positive and innovative practice across Wales which would benefit from spreading more widely.
- Funding for carer support services remains largely short term.
- Carers are not routinely being offered an assessment of their needs nor provided with information, advice or support.
- There is a wide range of information available but carers sometimes have to go to several places to obtain this and it not always easily accessible, especially at times of crisis.
- We identified two types of carers where support was most limited. These were parent carers for children with complex needs and carers of adults with mental health needs.

# Background

In 2016 the Care and Social Services Inspectorate Wales (CSSIW) changed its approach to evaluating the performance of local authorities in the light of the Social Services and Well-being Act 2014 (SSWBA). This change included greater engagement with people who have social care needs and their carers. For 2016/17 it was agreed that CSSIW engagement activity across the 22 local authorities in Wales would focus on the experience of carers. This work was led by CSSIW Area Managers.

# Why carers?

In 2015, the first Carers Assembly was held in Wales[1] and this identified a number of themes including:

- Rights and assessment.
- Provision of information.
- Respite care and cuts.
- Work and finances.

In addition, CSSIW noted that many of the annual reports produced by directors of Social Services across Wales said little about support for carers. This led CSSIW to identify the need to understand more about the experience of carers across Wales.

# The Social Services and Well-being Act as it applies to carers

The SSWBA broadens the definition of carers by removing reference to 'regular and substantial' levels of caring and increases the emphasis on well-being and prevention as important to carers. The Act includes a duty to consult carers so far as is feasible in the assessment of the cared for person and provides for possible combined assessment of carer and cared for person.

In relation to the carers needs assessment, carers no longer have to 'request' an assessment; this must be offered and include whether the carer is able or willing to continue in their caring role. The assessment should also agree the outcomes the carer wishes to achieve in day to day life, whether the carer works or wishes to (and/or) participate in education, training or recreation.

Local authorities now have duty to provide support to carers and it must also consider whether the carer would benefit from a preventative service or information, advice and assistance. Where a carer is assessed as having eligible needs, the council must put in place a support plan which focuses on the outcomes the carer wishes to achieve.

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[1] www.ccwales.org.uk/learning-resources-1/carers-and-the-act/

# What we did

CSSIW Area Managers attended forums and events that had been organized locally to support carers and held telephone interviews with carers so that we could hear about their experience. We looked at carers strategies and interviewed key officers and Council Members who were carers champions, and also met with and considered documentation from key partners including providers of services that supported carers, the health board lead on carers and the head of regional collaboration for carers.

Approximately 400 carers were involved in this work and this included young carers, parent carers and carers of adults with social care needs.

In addition we met with Carers Wales and discussed the emerging findings from their work on 'Track the Act' and feedback they have received from carers and carers organisations.[2]

We agreed four key lines of enquiry linked to the national outcomes framework and quality standards for local authorities. The outcomes CSSIW focused on were:

- Carers receive the support they need.
- Carers know their rights and understand the support that is available to them.
- Carers are equal partners and feel supported and valued for the care they give.
- The vision for support for carers recognises their economic contribution and is clear about the intended outcomes.

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[2] www.carersuk.org/wales/news-campaigns/track-the-act/track-the-act-survey-findings

# Our findings

Outcome: Carers receive the support they need.

Question posed: How well does the authority understand the needs of carers?

Most local authorities have carers strategies in place but some of these have not been reviewed to reflect changes under the SSWBA. More recently some local authorities have developed a new carers strategy in response to the SSWBA underpinned by the principle of ‘co-production’ and recognition of the need for a significant shift in thinking about how resources in communities can be better developed; such carers strategies strongly adopt a partnership approach with carers and the voluntary sector. It is too early to say whether the production of a strategy will result in improved outcomes for carers but they do provide an overview of the intended direction of travel.

Over the past 18 months, there has been significant activity in collecting and analysing data on a regional basis across Wales to support the development of Population Needs Assessments which include a chapter on carers. Carers have contributed to this work in different ways including through their representation on regional Citizens Panels and regional Partnership Boards. However, carers told us that most local authorities still need to do more to listen to, and act upon, the voices and views of carers.

A wide range of local services to support carers has developed across Wales including some innovative initiatives. These emerged over a number of years during the period of the previous Carers Strategy and as a response to locally identified need. The result is a patchwork of services, some of which have been ineffectively commissioned and often involving complex monitoring arrangements for small amounts of money, largely as a result of over reliance on short term grant funding. Possibly as a result of funding in this way, many services that support carers continue to exist with the uncertainty of short term contracts. A few annual reports of directors of social services in 2015/16 highlighted the need to review their support for carers, and the assessments and support available to them in the light of the SSWBA.

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. Additional support through website development and on-line resources for statutory and third sector providers, together with carers is vital.

However, overall there is evidence of a diminished strategic focus and action in relation to supporting carers previously driven by the expectation of the Carers Strategy. There is a view that moving lead responsibility from local authorities to Local Health Boards (LHBs) under the former Carers Measure did not have the impact intended. Often the carers lead officers employed by local authorities and LHBs, whilst individually committed to improving support for carers, have not been sufficiently senior to influence strategic decision making and action. There is also an evident risk that supporting carers is not owned as 'everybody's business' across social care and health teams and across the council and NHS.

**Outcome: Carers know their rights and understand the support that is available to them.**

**Question posed: How effective is the council in providing information advice, assistance and assessment and support planning to carers?**

There is a good level of information available across Wales via local authorities and the third sector with good links between local authorities and third sector carers groups and alliances with many producing information and regular newsletters. This does vary and in some areas traditional carers publications are less popular, with carers now accessing information through a range of social media sources. 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. The DEWIS web based information system has been rolled out in some counties and carers reported easy access to this webpage information. Where regional partnerships are strong then evidence of greater coordination is clear.

It is of particular concern that carers report that they sometimes struggle to find information, especially in times of stress. It is also important to note that some carers reported having no internet access and feel disempowered by the increased focus on web based information. Improvements are also needed in ensuring that carers information is available in a wider range of formats including for those with visual impairments, especially via the local authorities web pages.

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. Some counties have regular carer information days and carers told us about the warm human response they receive along with information leaflets and contact details of support groups and services available to carers.

Carers are clear that they want to have their stories heard and hold meaningful 'what matters' conversations with social workers, which are then responded to. This remains inconsistent across Wales and carers suggested the need to simplify the multiple sources and entry points for information and support of different types and levels provided by different sectors and agencies. Local authorities need to enhance social worker awareness of the breadth of information and support services for carers.

Whilst there is evidence that some local authorities have progressed in responding to the SSWBA in relation to supporting carers, others still have some way to go. Discussion with some staff demonstrated that the need for a new style 'what matters' conversation is not yet being applied to carers and further work is required to embed the new culture to meet the requirements of the SSWBA.

Access to a carers needs assessment is varied – some carers confirmed they had received an assessment and knew who to contact for support; others commented that the GP supported their access to a carers needs assessment while yet other carers said this was undertaken as part of the support provided to the person they care for. Carers reported duplication with them having to tell their story a number of times and in some local authorities the 'single point of access' is passing carers on for assessment without commencing an assessment through 'what matters' conversations. We also spoke to carers who were not clear whether they have had a carers needs assessment nor understand the relevance of conversations they have had.

The view of the quality and fitness for purpose of the carers needs assessment is mixed. Some Carers confirmed that where assessments have been offered and carried out generally their views are listened to. Carers reported a lack of face to face engagement which often led to no written confirmation of what had been discussed over the phone or of what outcomes had been agreed. It is also of concern that in some counties, concern was expressed by carers about being on a waiting list for a carers needs assessment to be carried out. Particular issues were identified about who does the assessments for carers of disabled children which has caused significant stress for parents.

We received positive feedback from carers and key partners where clear structures to support carers exist along with a clear understanding of using 'what matters' conversations underpinned by broader links across the council and its partners.
New community well-being 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 but this is inconsistent. The need for local authorities and the commissioned carers services to demonstrate flexibility and innovation in responding to what matters to carers is crucial.

**Outcome: Carers are equal partners and feel supported and valued for the care they give.**

**Question posed: What do carers say about: how well their needs are met?**

Carers report feeling that they are equal partners was a very mixed picture across Wales. Some carers reported being engaged and actively listened to as partner in the care of the cared for person, whilst others reported assessments as simply a tick box exercise. Some carers told us that they are actively involved in local groups and learn from other carers about how to access information and support, others feel they are consulted as a last resort. Some reported feeling nothing had changed following their assessment and so challenged its value.

As already reported, the availability of support for carers is varied. The better performing local authorities told us about a diverse range of flexible and creative provision including courses, counselling and direct payments to enable carers to make their own arrangements. Many local authorities had developed policies to support carers employed by the council and some counties had developed links with other employers, largely through third sector carers organisations. A few counties had also developed partnerships with job centres to support carers into employment.

A number of counties have also developed successful initiatives with health boards and notably GP practices which is often the first point of contact for carers; others have extended this to hospital wards and this area of development had often been driven by NHS involvement following the introduction of the Carers Measure.

However, other carers reported that where support is provided this is limited to provision of aids and adaptations or short breaks. In these local authorities it was difficult to evidence what was being provided to the carer in terms of their own support rather than support to the person they care for.

Young carers generally are well supported, however, there are an increasing number with complex emotional needs and the lack of child mental health services means that workers supporting young carers are dealing with some challenging and complex issues. Some local authorities have safety plans in place for young carers on who they can contact for support if needed. The issue of identifying young carers remains a concern; some young carers services have a waiting list for support and it is unclear how young carers are then supported whilst waiting to access the service. The role of education and the schools service is clearly vital, and again this is mixed across wales. Once young carers are identified the support provided appears to be strong. The development of marketing and promotion plans, web sites, engagement with the schools and youth service, accounts on Twitter and Facebook and engagement with Job Centres are all evidence of ongoing development work.

Many carers told of the benefit of having access to a short break service. There are differences in availability to such services between local authorities and between service user groups. Comments referenced the need for significant forward planning to enable carers to use short break care which meant that little help was available when short break was urgently needed. Many local authorities have reduced day care and short break services due to financial cuts but CSSIW has not been able to evidence if this has had a direct impact on carers.

Carers stated that they would welcome more information on Direct Payments especially in being able to use such payments more flexibly. Some local authorities are struggling with approaching this matter with creativity and listening to what matters to carers.

Support groups for older people seem to be universally available; however, where specialist support groups are required such as mental health and learning disabilities this is not always available in each county.

CSSIW's engagement with carers identified two types of carers where support was most limited. These were parent carers for children with complex needs and carers of adults with mental health needs.

Parents who are carers of children with complex needs, autism or behaviour that challenges told us of limited support. Diagnosis was sometimes seen as a gateway to services for children with complex needs, but parents sometimes reported their disappointment of no offer of support or services following a diagnosis. Children who had CAMHS services were not eligible for the same range of services as disabled children and this was identified as an issue that affected the level of support for the whole family.

Carers for people with mental health needs or substance misuse issues reported that even where they had received a carers assessment, it was rarely updated or reviewed and there was a lack of specialist support available that was locally accessible. Some carers reported that when they were in the midst of the 'chaos of a crisis' there was little support and they had to manage alone. Access to support was thought to be easier where a care co-ordinator was already allocated to the person with mental health needs. Carers also described periods of time when they were concerned for the safety and well-being of those they cared for and of the difficulties of accessing medical support and not being informed of issues because of the duties of confidentiality. They said that the cared for person would chose not to make use of the services available to them and this had a huge impact on the demands made on carers, they felt the strain this places on them wasn't acknowledged. Many of these carers were seen to be in a very anxious and vulnerable condition.

Outcome: The vision for support for carers recognises their economic contribution and is clear about the intended outcome.

Question posed: To what extent has the leadership of the council delivered a clear vision for supporting carers and involved its partners in this including carers themselves?

Local authorities need to quality assure and audit the work of its commissioned services more effectively, focusing more on outcomes for and voices of carers. It was apparent that local authorities do not have robust monitoring arrangements in place to determine the quality of the services they commission to provide information and support to carers. Whilst some local authorities have moved to focus on outcomes for carers rather than outputs in their monitoring arrangements, others continue to have a tick box approach to contract monitoring focused on policies and procedures, and a greater focus on the delivery of outcomes for people. Work with carers is supported through a range of models from a single carers officer, a single contacts monitoring officer or small teams of carers officers and aligned business support. Some local authorities audit the process of carers assessments taking place and being reviewed, in other local authorities the quality of assessments, inadequate timeliness of response and ongoing review was highlighted. As such there is inconsistency in oversight, monitoring of outcomes and quality assurance. This is an important area for development.

The ability and capacity of the commissioned services to deliver on the wide ranging carers agenda is a challenge and not one that is always recognised by commissioners. Whether these services can remain stable and sustainable within the current grant funding arrangements, and where historical service level agreements restrict innovation is a key issue. The importance of growing and coordinating this sector to ensure a robust and sustainable platform of service delivery was highlighted throughout CSSIW's work during the year.

As so much of the support for carers is provided through the commissioning of voluntary organisations it has resulted in a mixed picture as to local authorities' own engagement with carers through events, forums and information days and carers remarked on this absence. However we saw evidence of strong political support with many local authorities' having an elected member designated as carer champion and who were proactive in this role. Yet wider corporate recognition of their crucial role in driving, co-ordinating and delivering support for carers needs further development. The emphasis on safeguarding as being 'everybody's business' now needs to be focused on supporting carers 'being everybody's business'.

# Conclusion and next steps

There exists a strong evidence base that highlights the vital economic contribution made by carers and the importance of identifying and supporting carers in this role.

CSSIW's year long engagement with carers found some very strong practice in supporting carers, but this is not consistent across Wales.

In the drive to transform services in line with the SSWBA, support for carers has slipped down the agenda and local authorities, with their partners, need to ensure that carers right to assessment and support is well understood and enacted by frontline staff.

The vital importance of timely access to information, advice and assistance was a key theme repeated by carers and local authorities need to work with partners to ensure accessible and effective provision.

It is also important that carers strategies are refreshed and coherent commissioning plans are in place that reflect the responsibilities laid down in the SSWBA. These need to be predicated on principles of co-production and what matters to carers and can demonstrate how positive outcomes for carers will be achieved.

CSSIW will continue to engage with carers as a core part of its inspection and performance review programme with local authorities and will continue the dialogue with Carers Wales to inform this work.