

Inquiry into the impact of the Social Services and Wellbeing Act 2014 in relation to carers - supplementary evidence

Introduction

Carers Trust Wales exists to improve support, services and recognition for unpaid carers in Wales. With our Network Partners – local services that deliver support to carers – we work to ensure that information, advice and practical support is available to carers across the country.

During 2017-2018 the Carers Trust Wales Network reached over 34,000 carers, employed 480 staff and was supported by 475 volunteers.

Carers Trust Wales delivers practical support and information to carers and to those who work with them including: schools, social workers, nurses, pharmacists and physiotherapists. We also seek to influence decision-makers, the media and the public to promote, protect and recognise the contribution carers make, and the support they deserve.

Following giving oral to the committee we would like to provide supplementary evidence to highlight:

- **The role of third sector organisations in collecting data about carers**
- **The level of assessments undertaken by carers services as part of delivering preventative services effectively**
- **The role of third sector organisations in utilising carers' voice to shape services**

The role of third sector organisations in collecting data about carers

Third sector organisations that provide services to carers almost always undertake assessments of carers needs when they present to a service. For many carers this results in a detailed assessment of their needs and the development of a corresponding support plan.

Many young and young adult carers services routinely use Multidimensional Assessment of Caring Activities (MACA) and Positive and Negative Outcomes of Caring (PANOC)¹ which are recognised tools to understand caring needs and to inform conversations around support needs. These will be recorded and provide rich data about the levels of care undertaken at a local level.

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https://search3.openobjects.com/mediamanager/manchester/fsd/files/young_carers_multidimensional_assessment_caring_activities.pdf

Similarly, carers services use a range of tools to capture the needs of carers of all ages and the extent of their caring role.

However, as indicated in oral evidence, there are rarely routes for this information to be shared in a systematic way with local authorities, Local Health Boards or Regional Partnership Boards.

Individual Carers services put substantial effort in to meeting carers needs and therefore, within funding restrictions, are well placed to respond in an agile way to changes in local carer need. The richness and depth of data collected regarding the carers they support enables them to develop in ways that best meet carers' needs.

We are concerned that some public-sector bodies have indicated to us that funding streams, such as ICF, are too restrictive to enable them to work with the most effective organisations. For example, their inability to fund or work with national organisations to help them develop evidence-led decision-making processes can lead to commissioning approaches that don't make the most of the expertise available. Regions may duplicate research or fail to share learning because of an inability to commission research, evidence or information sharing at scale.

Just as local and regional carers services are experts in supporting and working with carers in our communities, it is also vital to recognise the valuable role that national third sector organisations such as Carers Trust Wales have in providing a Wales wide focus on unpaid caring. National organisations have a crucial role to play in delivering Wales wide research, innovation and co-produced solutions with and for carers and by supporting the professionals who work with unpaid carers directly.

The negative impacts of caring on carers themselves (and their families) mean planned support and sustainable investment for unpaid carers should now be prioritised as a national challenge. Delivered appropriately across sectors this will bring significant benefits to the health and wellbeing of carers and their families, save the economy millions of pounds and do much to support the pressure on our public services.

The level of assessments undertaken by carers services as part of delivering preventative services effectively

As highlighted during the oral evidence session and in our written evidence, not all carers will need a statutory needs assessment. For many carers their needs are adequately understood and met by local third sector organisations. It is important that any recommendations made by the committee recognise the value carers place on being able to access support without formalising their needs.

For many carers accessing help, support and advice through local, trusted, third sector organisations holds less stigma than achieving the same support through statutory services. Whilst it is important that the stigma of accessing appropriate support through statutory assessments is addressed it is equally important to recognise the current barrier this presents.

Local third sector organisations are uniquely placed to work alongside carers to identify their needs and to find ways to meet them before they reach crisis point.

The preventative value of carers services cannot be underestimated and in large part this can be attributed to their accessibility for a range of carers. It is crucial to utilise the relationships carers services have developed within the communities they serve ensuring that carers are signposted to the most appropriate level of support, which most often will be the preventative services provided by carers services.

Our research shows that the co-location of services within centres is consistently described as contributing factor to improving carers' awareness of their rights and confidence to access the support to which they are entitled.

Additionally, carers services play a crucial role in securing funding for the support carers need. Based on their expert understanding of the needs of their local population carers services are able to develop innovative and impactful projects and approaches and are often responsible for generating the funding for them. In many cases, where carers services are commissioned to deliver statutory services, they will fundraise and work with grant giving bodies to supplement income in order to be able to deliver the service effectively. Carers services play an essential role in generating funding for preventative services and it's important to emphasise the value carers services have in both the delivery of services and ensuring their sustainability. Unquestionably the Integrated Care Fund and Transformation funds could create a much smarter, more sustainable pathway of support for unpaid carers. However, for impact to be maximised the expertise and insight of local and national third sector organisations (both in service delivery and the funding of impactful services) must be better captured and utilised.

The role of third sector organisations in utilising carers' voice to shape services

Third sector organisations are experts in engaging carers directly in the shaping of services. Whilst the challenging financial climate has made meeting demand impossible, carers services continue to ensure that their direction of travel is shaped by carers themselves.

For services to be effective it is essential that they are co-produced with carers. Carers must be supported as key contributors to the development of service specifications and involved in commissioning processes.

The National Population Needs Assessment identifies that improvements must be made to the involvement of carers in service development. Our Network Partners consistently highlight the importance of involving carers in service design and development. However, at a regional level there remains concern about engagement being tokenistic or repetitive it is important to note that engagement needs to be meaningful and avoid repetition.

To join-up carer engagement it is important that strong relationships are built within each region between:

- Carers services
- Carers representatives on Regional Partnership Boards, and relevant associated groups that sit under them
- Carers Leads within local authorities and local health boards
- Community Safety Partnerships
- Public Service Boards
- Local and national third sector organisations that support carers

Some recognised approaches to involving carers in service development identified by our Network Partners include:

- Carers representatives on panels, boards or groups
- Developing carer forums and encourage strong links between service providers, commissioners and the carer forums
- Carers advocates or champions within services and on decision-making bodies and boards
- Focus groups to help inform the shape of services or how they're delivered
- Involvement in training for frontline professionals and decision makers

It is important to recognise that carers are often time-poor. Additionally, whilst they are experts in their lived experience they may not be practised in engaging in formal consultations or meeting processes. Therefore, our Network Partners reflect that engagement opportunities must be planned sensitively with adequate time, thought and investment put in to supporting carers to engage effectively. Some common good practices include:

- Providing replacement care
- Reimbursing expenses
- Time banking
- Developing buddy systems and opportunities for peer-to-peer engagement between carers
- Involving carers in the development of consultation resources and in the setting of agendas for formal meetings
- Circulating papers and questions ahead of meetings and consultation events both for feedback and to allow carers to prepare their thoughts and answers
- Developing shadow boards
- Holding pre-meetings to inform carers and to support them to engage effectively
- Consulting carers on appropriate venues and convenient meeting times
- Meeting with existing groups of carers to minimise the impact sharing their views has on their free time. This is something carers services are well placed to facilitate.

