Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Gwella mynediad at gymorth i ofalwyr di-dâl

This response was submitted to the Health and Social Care Committee consultation on Improving access to support for unpaid carers.

UC26: Ymateb gan: Adferiad | Response from: Adferiad

Adferiad provides services to and campaigns for unpaid carers who provide support to people living with a severe mental illness (including schizophrenia, bipolar disorder, and other conditions involving psychosis or loss of insight), people affected by addiction, people with a co-occurring diagnosis, and other unpaid carers whop support people with a wide range of conditions.

We are governed by our members who elect our Board of Trustees, which has a strong representation of both carers and service users, and we support over 30,000 people, delivering services across Wales and in Lancashire. We are a specialist third sector organisation that supports people with the highest needs.

We work with people, not conditions or diagnoses. We do not restrict who can seek support from us: for us it's about the person as a whole, not identifying a "hole" in the person.

Adferiad campaigns with and on behalf of the people who use its services, their families, carers, and friends, and for those who need its voice as they are not receiving the services they need.

While we understand that the inquiry is seeking to examine the provision of and access to support for unpaid carers in general, given our long history and breadth of service delivery we feel we have something unique to say about the somewhat unique role played by unpaid carers of people with severe mental illness and poor mental health.

1. **Main barriers faced by unpaid carers in accessing the support they need; including any specific challenges for carers based on factors such as age, ethnicity, or where they live.**

   In summary:

   - Not being listened to, valued or included in Care and Treatment Planning. Carers often feel excluded, with some coroners' reports highlighting preventable tragedies caused by poor engagement.
   - Many do not identify as carers and are put off by the "carers' assessment" terminology – sometimes believing that what is being assessed is their ability as a carer, not their needs. However, while they may decline an assessment, they are often ready to accept offers of support or advice.
   - Statutory bodies rarely identify carers on time. A simple step would be to include carer information in hospital admission forms and share across agencies.

- Withdrawal of social workers from some CMHTs has widened the gap between health and social care, leaving carers to navigate a complex and disconnected system.

Adferiad has been receiving feedback from unpaid carers over many years; via numerous surveys we have conducted, through forums and focus groups, and from carers whom we provide services to. The main message we hear time and time again is that unpaid carers face many barriers because they are not listened to, are not valued, and are not included in care and treatment planning.

Where this relates to a carer for someone with a severe mental illness, this has sometimes led to a tragedy. Numerous coroners' reports have raised serious concerns about the lack of care, and family engagement with care and treatment planning, leading to a preventable loss of life. Adferiad is currently working with NHS Performance and Improvement to find solutions to the barriers that unpaid carers face and will be reporting progress towards the end of the year.

A significant barrier is the language and terminology that is used to describe carers. Most people who provide unpaid care do not identify as a 'carer'. They identify as a parent, or a sibling, or as a friend or neighbour. Many carers are also put off by and do not relate to the term "carers' assessment". We have heard many people say that they believe in some way that this means their ability as a carer is being assessed. When asked if they want a carers' assessment, many people say 'no'. When asked if they need any help, advice, or support, the same people often answer 'yes'.

A further barrier that unpaid carers face in accessing support is being identified as a carer in the first place. The Social Services and Wellbeing (Wales) Act 2014 places a duty on Local Authorities to first identify a carer and then proactively offer support. In reality, this does not happen. Adferiad is proposing that when someone is admitted to hospital, the ward admission form includes a 'carer impact assessment', asking whether the patient has an unpaid carer (in addition to what is already asked about a next of kin). Where a carer is identified by one statutory or third sector body, there needs to be a process in place to share this information across agencies and create a referral pathway to services that can provide support to the carer.

Another major barrier is the lack of join-up between social care and health. Both the Social Services and Wellbeing Act and the Mental Health Measure emphasise the benefits of providing an integrated service to carers. This includes a single health and social care assessment and a single care plan or care and treatment plan. Over the past few years, services have become less integrated. Social workers have pulled out of Community Mental Health Teams in many areas, and carers struggle to understand how to navigate the system and which professional they need to contact. Carers are struggling to navigate the complex health and social care landscape.

2. Current availability of respite care across Wales, including levels of variation across regions:

In summary:

- The term "respite" should be avoided as it carries negative connotations. Maybe "carers' breaks" is a more appropriate, respectful and empowering term.

- Access to respite care varies widely across regions, with significant inequality in provision.
- Carers should be able to determine whether the break supports them directly or it involves them helping the person they care for.
- The Amser Programme demonstrates the value of flexible, short breaks tailored to the needs of carers and should be expanded as a model of good practice.

Use of the term 'respite' should be avoided - the term is often synonymous with having relief from something difficult or unpleasant; it has negative connotations. Rather, terms such as "carers' breaks" or "caring interval" should be considered.

Adferiad itself provides many services relating to carers' breaks. We believe the choice of what sort of break should be determined by the carer.

Welsh Government's Amser programme is a lifeline for carers needing a break, providing funding and support to make arrangements. However, the criteria should not be limited to what one person may deem respite; for many carers, being able to check in on their loved one during respite (sometimes being cared for in a mental health unit located far from home) is respite itself. Having a relaxation/beauty treatment is not going to relieve the anxiety of a carer who is unable to afford to visit the person they care about."

3. **Extent to which the demand for carers support services is being assessed and addressed, and current levels of unmet needs:**

   In summary:

   - Local authorities and health boards do not systematically assess demand (despite the duty to do so), leading to great unmet needs.
   - Data on the needs of carers is inconsistent, siloed and rarely shared across agencies.
   - Provision is reactive, rather than proactive, as a result of the lack of joint planning. This leaves carers without timely support.

The Social Services and Wellbeing (Wales) Act 2014 places a duty on Local Authorities to first identify a carer and then proactively offer support. In reality, this does not happen. Though they are essential tools, Care and Treatment Plans (CTPs) are frequently inconsistent, poorly coordinated, and do not take into account carers' lived experience.

Independent coordination can guarantee that CTPs fulfil their commitment. We recommend care and treatment coordinators are recruited within Third Sector organisations, independent of local authorities and health bodies, to ensure accountability and cross-sector integration. In addition, we call upon statutory bodies to ensure genuine co-production of services with unpaid carers and those with lived experience.

As previously mentioned above, Adferiad is proposing a 'carer impact assessment' be included on hospital admission forms, asking whether the patient has an unpaid carer (in addition to what is already asked about a next of kin). Where a carer is identified by

one statutory or third sector body, there needs to be a process in place to share this information across agencies – a "tell us once" approach

4. **The role of Regional Partnership Boards in the provision of support for unpaid carers, and the effectiveness of current commissioning practices in services:**
   In summary:

   - RPBs have been inconsistent in prioritising unpaid carers, and there is significant variation between regions.
   - Carers' voices are not taken into consideration in commissioning decisions, leading to services that don't reflect lived experience and reality.
   - There is a need for stronger Welsh Government direction to ensure carers are meaningfully involved and that good practice is spread consistently.

A report by Carers Wales recommends that Local Authorities and Health Boards should work regionally and across sectors within RPBs and beyond to ensure greater consistency in the way that information, advice and support for unpaid carers is offered and provided. We fully concur with recommendation and have experienced anecdotal evidence of inconsistency within and across regions.

Adferiad advocates for the need for shared decision making; carers' voices need to be heard and listened to. Carers need to be involved and fully engaged in the decision-making process so that any commissioned services reflect the lived experiences of what it is like to be an unpaid carer.

5. **The actions required to improve implementation of the Social Services and Well – being (Wales) Act 2014 provisions for unpaid carers (including Carers Assessments and support plans):**
   In summary:

   - Duties to identify carers and offer support are not being met. Carers must be proactively engaged, instead of being left to self-identify.
   - The language used such as "carers' assessment" must be reformed to remove barriers and encourage participation and uptake.
   - Health and social care integration should be prioritised, with single assessments and joint care and treatment plans.
   - Carers should be formally recognised in planning and decision-making processes as a right not as an afterthought.

The actions above draw together the points raised in response to this inquiry and emphasise the importance of a) properly identifying carers in the first place and b) ensuring the language and methods used are appropriate, informed by lived experience, and anti-discriminatory.

Much of the problem of implementing the provisions of the Act relates to the dysfunctional relationship between health and social care, whereby those with the most complex of needs and in the most challenging of circumstances are required to navigate two, often entirely separate systems.

We frequently hear of increasing numbers of carers experiencing their own mental health issues because of the challenges of caring. Actively engaging carers in care planning and offering them support reduces the need for them to access mental health services. In addition, confidentiality is a major issue. There is inconsistency in how information about a patient is shared with their carer, and a lack of understanding from staff that not having consent to share does not stop them from listening to the carer, who will be able to provide further insight into the health and wellbeing of the cared for. A patient may report that everything is fine, but the carer may know they are not taking medication or further isolating themselves. The carer's voice needs to be heard to ensure appropriate support and treatment is in place.

We cannot understate the fact that support for carers, their inclusion in the care and treatment planning, and their active engagement throughout, are intrinsically linked to the successful implementation of statutory provisions for unpaid carers.