

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.](#)

**UC16: Ymateb gan: Fforwm Rhieni a Gofalwyr Pobl ag Anableddau Dysgu Cymru Gyfan | Response from: All Wales Forum of Parents and Carers of People with Learning Disabilities**

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Submitted by Gwen Anslow on behalf of the All Wales Forum of Parents and Carers of People with Learning Disabilities [REDACTED]

Confirming we are happy having our organisations name published with our response.

We have permission to share all examples cited in this response, but we have taken out all identifiable information and do not reference to any individual experiences.

**Consultation response**

There is still lack of adequate respite provision across Wales for parent carers who are caring for somebody with a learning disability. We are still seeing a post code lottery between regions of good provision including creative short breaks and other areas where there is a complete lack of any opportunities.

One of the biggest issues we are seeing at the forum in terms of barriers to respite, is the lack of replacement care for carers to take a break. In some local authorities, this is often non-existent. There is also an added element of complexity when the individual who needs the replacement care have added needs; for example, specific feeding which requires staff to be trained or any kind of care plan which requires more than one staff. As part of the development of the Short Breaks Cooperative, we have asked family carers to describe the biggest barriers to respite and short breaks, Cost at 43%, Difficulty in finding replacement care at 41% made the majority of respondents to accessing regular breaks. A

With the current Amser funding, what would be a solution is to allow flexibility for carers to be able to purchase care and support that would allow them to take a break. This would further improve and enhance current legislation around the right to respite. It also falls in line with the Wellbeing of Future Generations act as it gives voice, choice and control back into the hands of citizens and has lasting positive effects also on the cared for in the longer term by addressing their respite needs now, rather than later when it becomes an emergency.

If money in this pot is being given to 3rd sector organisations to explore creative and alternative options such as our Seibiant project, the money that is provided to the public sector including the regional partnership boards, should be used to provide replacement care. The evidence also suggests that one of the benefits of supporting third sector organisations with these approaches is that it also represents better value for money and more outcome focused services.

We understand work is currently underway looking into the lack of carers assessments that are being undertaken but it is important we strongly emphasis that a carers assessment is the gateway to receiving care and support. If these are not

being adhered to, carers are missing out on the care and support they are entitled to including respite services.

So, within our response, we want to highlight what we know really works for our families, what the barriers are and our recommendations to improve respite care for families in Wales. Putting families and individuals at the centre of the respite and short breaks process is critical to ensure those breaks work for them.

### **What works**

Allow families the opportunity to choose what a break/respite looks like to them.

Providing them with the freedom and tools to make the decisions themselves.

Linking up with local tourism and leisure sector to showcase the best of Wales.

Carers Assessments which are offered without barriers and give timely support with access to respite.

Good and reliable information regarding accessibility in the area.

On-going support from third sector, statutory and community partners to enable carers to access these opportunities.

### **Barriers**

The All Wales Forum is currently in the process of setting up a Short Breaks Cooperative, run by families for families. As part of the setting up process, we ran a survey asking parents “what is the difficulty in having a break?”; the first answer was cost and the second replacement care. Replacement care was also highlighted as an area of concern to parents getting involved with a co-operative like this due to time constraints and capacity.

We believe respite breaks for families should be funded and delivered in a flexible way that works for families. For many, this may involve their children being with them but for many, a break may mean going away on their own or with a partner/friend.

The spirit of short breaks should allow these options to be available. However, going away without your child is not an option for many of our families due to the lack of replacement care available.

Lack of accessibility information. Although there are incredible charities of the likes of Euan’s Guide in the UK and Piws in Wales which are improving this kind of information, it’s still a barrier for many families, especially when organising longer trips which are even an hour away from home. A wrong measurement can make a booking unusable for a wheelchair user. An unsecured garden can turn a relaxing break to an absconding-risk nightmare. A parking lot that is too far from the venue could be the make or break of a day out.

Financial. The added costs of disability are always to be taken into account when looking at a family with disabled loved ones. Whether it’s the added cost of insurance or having to rent a car to make room for medical equipment or having to book a bigger room or a specific room because it meets their needs. Maybe having to get a taxi because public transport isn’t accessible or the cost of ordering emergency supplies if something goes wrong, or there are food restrictions. You can never underestimate how much elevated costs stop carers from taking a break, especially in the ongoing cost-of-living crisis we are currently living.

Carers Assessments – there are families in different local authorities that simply cannot access any support or respite because they can’t get a Carers Assessment. Whether it is because services are so depleted, they are simply not offering

assessments or because there have been so many cuts to staff there aren't enough people to carry the assessments out, so they have been paused or the waiting lists are so long that by the time they can offer a carer assessment the family is already in crisis and has had to lean on emergency services with outcomes that might have a devastating impact on the family, for example, having the loved one sectioned or moved to a facility which is far away from home and not an appropriate location, as highlighted by the Homes Not Hospitals campaign.

### **Recommendations**

Amser funding provided to public bodies to be used for replacement care.

Ensuring that all local authorities are offering Carers' assessments and that there is a core offer across Wales, allowing Carers to access support services.

Celebrating and showcasing accessible businesses and venues

Commitment to keeping costs accessible for carers, for example waiving the Overnight Visitors Levy for Welsh carers staying in Wales in the Visitor

Accommodation (Register and Levy) Etc. (Wales) Bill.

Consciously choosing to grab the opportunity to take co-produced and carer-led solutions and innovation forward properly (like Seibient/amser) and the short breaks coop ideas/pooled budget solutions. This would better enable carers to have the tailor-made support they're entitled to under the SSWB act. Rather than just tinker around the edges with what's always been on offer and keeps, for so many families, falling short of what is needed. If we took some bold steps, we could really shift this are towards a preventative approach of support and not just a reactionary one that deals at point of crisis.