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

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

UC14: Ymateb gan: Cronfa'r Teulu | Response from: Family Fund





Family Fund response: Improving access to support for unpaid carers

 The 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

Unpaid carers face a wide range of barriers in accessing the support they need. These challenges cut across financial insecurity, lack of accessible and appropriate services, difficulties with travel and transport, and limited respite or childcare provision. They are often compounded by geography, age, and circumstance, leaving carers isolated and unsupported.

Financial barriers and affordability

A recurring theme is that carers cannot afford the additional costs associated with caring or accessing breaks. Families spoke about being unable to afford holidays, day trips, or even routine leisure activities:

- "We can very rarely go on days out during school holidays due to lack of money."
- "I love how family fund help us poor people do things I would never be able to afford to do with my disabled child because things are so expensive to do these days."

Carers emphasised that even where opportunities exist, cost prevents them from taking part. For some, this means never getting a break, with direct impacts on their wellbeing and their child's social participation. Affordability also intersects with rurality and transport needs, where families face rising fuel costs or lack a car altogether. This creates exclusion from community opportunities:

 "Young carers don't operate well in rural areas, and we get missed. They have loads of trips and clubs, but we can't get the children to the events."

Inadequate respite and childcare

Many unpaid carers cannot access appropriate respite, leaving them unable to balance caring responsibilities with work or rest. Families reported long waiting lists, oversubscribed holiday clubs, and an absence of tailored provision. Carers of children and young people with higher support needs highlighted that generic childcare was not suitable:

- "They have complex needs, but they don't need to be spoken to like 3-year-olds and patronised... They need calm quiet surroundings to stop them melting down."
- "My daughter needs to be supervised at all times due to her having no danger awareness... there is no funding for her to have this constant supervision."



This lack of provision places a disproportionate burden on parent carers, especially where there is no wider family network. The absence of trusted respite makes it impossible for many carers to rest, work flexibly, or even manage daily life.

Limited appropriate and flexible support options

Support is often designed without sufficient flexibility to meet the diverse needs of carers and the people they care for. Families valued support that allowed them to choose what works best for them, for example, vouchers for games at home instead of trips away, or holidays where activities and food were included so costs did not escalate.

- "We got a gift voucher for Amazon, and we used it for board games as my son really enjoys these and we spend time together, which is nice."
- "Butlins has so much to do all the time... I didn't worry about organising activities or budgeting for them... This meant I got to feel I was having a break as well."

This highlights the importance of providing a range of options that recognise differences in age, disability, cultural background, and family preference.

Equally vital is the quality of care provided when families do access support. When a parent entrusts their disabled child to the care of staff, it is not a casual handover, it is an act rooted in vulnerability and hope. These children often face complex physical, emotional, or sensory challenges that require more than basic supervision; they need understanding, empathy, and skill. Yet, a lack of adequate staff training can leave parents feeling anxious and unsupported, knowing that the person responsible may not fully grasp the intricacies of their child's needs. Proper training is not just a procedural necessity, it's a matter of safety, dignity, and trust.

Transport and travel barriers

Transport is a consistent challenge, particularly for carers in rural areas and those without access to a car. Reliance on expensive private transport, or the lack of suitable public transport, excludes carers and their children from support, peer networks, and leisure opportunities:

 "Because my son can't travel on public transport he needs to be dropped off and collected everywhere he goes. This has a huge impact on the only car we have and fuel costs."

These travel challenges particularly affect carers outside urban centres, where specialist activities or carer groups are not locally available.



Accessibility, equipment, and inclusion

Carers frequently reported difficulties accessing equipment and opportunities that allow their children to participate on equal terms. For some, this is about specialist equipment like wheelchair adaptations, while for others it is about age-appropriate and inclusive activities for older children and young adults:

- "After college what is there to do for young adults?"
- "Equipment e.g. mountain bike wheels for my granddaughter's wheelchair."

Without accessible and inclusive provision, carers feel excluded and unsupported in preparing their children for adulthood.

Emotional strain and barriers to seeking support

Many carers described exhaustion from constantly advocating for their children's needs. This leaves little capacity to seek support for themselves, and can create feelings of isolation:

 "Most of my energy has gone into advocating for the health, education, and wellbeing of my youngest two children... times I was left feeling alone and blamed."

Where carers do receive support, they emphasise the relief of not having to struggle alone and the importance of being reminded that help is available.

2) The current availability of respite care across Wales, including levels of variation across regions

The availability of respite care across Wales is limited, fragmented, and marked by regional and funding variation. Families raising disabled or seriously ill children consistently report difficulties in accessing reliable respite and short breaks.

Take a Break Wales funding

Family Fund currently receives £360,000 per year from Welsh Government to administer the *Take a Break Wales* programme. This provides grants for short breaks, or to enable breaks from caring within the home, supporting the Welsh Government's commitment to ensuring carers have reasonable opportunities for rest and a life beyond caring. Family Fund also provides signposting support to address wider family needs.

However, families are acutely aware of the reduction in funding over the last decade. In 2015/16, Family Fund received $\mathfrak{L}2.5$ million annually to support families in Wales. Since then, the funding has significantly decreased, with the budget capped at $\mathfrak{L}360,000$ for the last four financial years, despite rising costs of living, greater complexity of need,



and increasing numbers of disabled children. The proportion of potentially eligible families in Wales being reached is significantly lower than in the other three UK nations. Analysis of the data from the annual <u>Family Resources Survey</u> indicates there are around 35,000 families on low incomes raising disabled children and young people Wales, but we were able to award only 983 grants last year. Across the rest of the UK, we support around 13% of eligible families, compared to just 3% of eligible families in Wales.

As one parent noted:

• "Honestly, we have struggled with constantly increasing costs as our son gets older and his behaviour gets even more difficult to manage... So, this year, living in Wales and not having the help of family fund to pay for a holiday, it has been a loss that we have really felt."

This drop in available funding has resulted in fewer families receiving respite, narrower eligibility windows, and greater competition for grants.

Limited and inconsistent access to breaks

Families describe long periods where grant applications in Wales have been closed due to lack of funds, creating a postcode lottery in access to respite. For carers already under significant strain, this uncertainty adds stress and compounds isolation:

• "The one thing that has been frustrating is that Wales application has been closed for a long time and has been a struggle for help in Wales... we have felt very isolated and not many places to turn to."

The short application windows further disadvantage families who may not have the time, energy, or digital access to apply quickly. This creates inequity across regions and between families, with some receiving support while others miss out entirely.

The importance of respite to carers' wellbeing

Where families do access respite, the benefits are transformative. Breaks, whether short trips, holidays, or support within the home, allow families to step outside their routines, reduce financial pressure, and focus on wellbeing:

- "It was always a relief to go on a holiday provided by family fund as it took us out of our very strained routine at home for a week, and gave us something positive to look forward to in the year."
- "It would just be nice to have some escapism. Day trips, weekend trips. It would help keep my child occupied and not fixate on worries such as her eating disorder, autism, and ASD."



Respite is not a luxury; it is essential to maintaining carers' capacity to care, preventing family breakdown, and supporting disabled children's inclusion in family and community life.