

Briefing for Powys County Councillors

By Credu Connecting Carers

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Co-producing Respite with Young and Adult Carers

In other words finding creative ways, with young and adult Carers, to keep life manageable and sustain capacity to continue caring

About Carers and Young Carers in Powys and why supporting Carers matters for people in communities and public sector budgets

- There are at least 16,000 unpaid Adult Carers (people who look after a family member who is unwell or disabled) and well over a 1000 Young Carers (Census 2011 and BBC Research indicating that 1 in 12 children become a young carer).
- Caring can be rewarding but can profoundly impact upon the health. 61% of carers report that caring has impacted upon their health. (Carers UK (2018))
- Carers save the Welsh public sector over £8 billion per year with the care and support that they provide. (Carers UK (2018))
- Working well with and involving Carers will reduce overall spending on care. (Carers Trust (2020))
- The Social Services and Wellbeing Wales Act (2014) gives carers the same rights as those they care for and as such they are referred to throughout the Act.

The Respite Challenge in Powys

- Powys County Council lead officers and cabinet members have spent time listening to Carers at biannual carer led events facilitated by Credu. Since 2017 in particular, the need for easier access to flexible respite has been a key issue for Carers. Whereas there were stunning examples of success for some families, others felt that access to meaningful respite was a very serious issue.
- Carers described how sometimes respite means time apart and access to care workers / care homes / foster carers but that respite can actually be found in all sorts of different and creative ways. Also, respite does not always mean time apart from your loved one, but support to have quality time together. Some of this costs money and some does not cost a penny. For example, one Carer drops his wife off at café where she knows lots of people and feels happy and settled, while he takes a walk for an hour. This man has been caring for his wife for many years so is very experienced and has learned to find ways to make life manageable. It was argued that carers and those new to caring need to have the time and space to think about what is really important to them and what is their personal idea of a break is. It was argued respite support should be very personalised and bespoke if it is to have value.

Powys County Council and Carers working together to develop a progressive solution

- The Regional Partnership Board has a Carers Steering Group (which started in early 2019) made up of Carers and lead officers from Health, Education and Social services. In response to the listening work, council officers and members had done, they involved Carers significantly in the design and commissioning of the 'Co-producing Respite Project' using Intermediate Care Funding. This approach to listening, designing and commissioning services with Carers has national recognition and featured in a pan Wales Carers Trust Conference.
- Credu Connecting Carers won the contract to deliver the project and the project became live in November 2019. The project is worth £106k per year which covers a co-ordinator, and a respite budget to test innovative and personalised approaches.

Impact to since November 2019 and through lockdown

- 138 individuals have benefited from the project to date, 100% report that the project has supported their wellbeing and capacity to continue caring. Lockdown has delayed some aspects of the project, but it has been adapted to help families cope and find respite during the lockdown period. The feedback and the comments have been powerful and positive. Here are some examples:

Example 1

"I dare to dream these days. Before ... I was existing just get through the day. I feel my life has purpose now. Credu [as a result of funded projects and approach] gave me a reason to live."

Example 2

*'... its actually my lifeline and my new found therapy. My son has ASD, ADHD and mental health issues. ... Sometimes his lows mean ...he looks for ways in which he can end things, as a Mum that breaks my heart. But in order for me to balance my own mental health and wellbeing and to support him to the best of my ability, along with working every day, I found going for a bike ride every morning before he got out of bed really helped me deal with whatever the day threw at me. At the beginning of this week my bike gave up and literally fell apart, as I'd probably ridden it to death and far more than it was ever designed for, as it was a teenagers bike! I put it back in my garage and sat on the floor and literally cried, as I felt a sense of panic come over me....
... I'm so grateful for the support from yourselves...for a new bike , I've felt lots of emotions.... Thank you from me and my son, he now has one happy Mum 😊'*

Case Example

Parent Carer of an adult son with autism was experiencing significant distress as her son's anxiety levels were spiralling. His main strength and passion is creating music using computer technology and his computer was no longer working. When Credu listened to the Carer and listened for the strengths in the family and what would really make a difference, we were able to fund a second hand computer with music software. The son has regained access to his life's passion and his mother / carer now has endless hours of respite.

As well as positive feedback from the carer, this is some feedback from her son:

'Just to let you know that BBC Wales played one of my songs on Saturday night. I did mention the fact that I was only able to make the songs thanks to the donation of the laptop I received from Credu [as a result of ICF funding].

The song is played 2 hours 11 minutes into the show.

<https://www.bbc.co.uk/sounds/play/m000k29I?fbclid=IwAR1xg7qArWFnZLnNdCLUJZxmZuGyp88bOlOv2Fnf1nliY70oTB8TKjL0bUc>

Cost / Benefit

Credu and Powys Regional Partnership Board are about to undertake an evaluation and a cost benefit analysis. However, you will see from these examples (and the examples in the appendix) that small amounts of money can go a long way. Individual respite grants ranged from £22.00 to £679 in the last quarter, yet the extent to which they are enhancing the quality of life of Carers and their families is profound.

Critical success factors

- Listening to understand what is fundamentally important to each carer and group of carers. This sounds very simple but Powys CC and Credu has invested significantly in training, supporting and mentoring all staff and volunteers to listen skilfully.
- Value every individual and notice, acknowledge strengths, and respectfully support people to identify solutions and as far as possible take action for themselves.
- When we focus not on what we can afford but what is possible with carers, we create solutions of high value, but very often, not at a high cost.
- Keep processes very simple so that we can do what matters when it matters to Carers (we work to Carers timescales as much as possible).

Next steps

- Undertake a rigorous evaluation with Carers at the heart of the process.
- The project continues until March. But may continue for a period depending upon ICF funding.
- Explore how the learning and benefits from this project can be embedded in services that support Carers and their families.

There are more elements to the project than can be outlined in a sort brief. For further information, please do contact Marie@credu.cymru and take a glance at some of the stories in the attached appendix.

APPENDIX: Some Narrative Examples of creative approaches to finding respite during the lockdown period

- ❖ I family whose teenage daughter normally goes to a special school was struggling with lockdown and the break in routine. She really missed the adult size sand table at school. The family spoke with a local carpenter and he had one made especially for her that would grow with her. The daughter could now happy playing in the garden helping the rest of the family to get on with whatever they wanted to do. CL1917 cost £160
- ❖ A family with a child with Autism and a new baby really wanted to spend more time In the garden together. They ask for some fun play equipment including water pistols and garden games. This really made lockdown more fun and they were all enjoying the garden. However, they also became more involved in Credu's others activities- they attend the ASD zooms, virtual camp and twitch stream sessions. After doing some activities with the WCD team they are even planning a trip to go and see their sons new friends. The son does not go to school and had no friends before. The parents have told us that he is chatting to his new friends online, playing in the garden and spending more time with them as a family 'we should have done this years ago' CL10544 £148
- ❖ We have a parent Carer who is also a nurse. She has been working full time and more during lockdown and felt so guilty that she was at home more and when she was she had to keep her distance from her children. What she thought would make a difference to her was a trampoline for her children to use when she was at work. While she was working the thought of them happy and playing made her feel better. Seeing photos of them during a shift was a massive lift. CL 11859 £249
- ❖ We had a couple come to us as they had heard about Credu, they asked what we could support with. The husband had been diagnosed with a heart condition which had restricted what they could do. They used to love going on holidays abroad and travelling. They had imagined doing this a lot in their retirement. We talked a lot about the adventures that they had already gone on, it was a lovely conversation. We then asked them to think about what would make their home a lovely place to be and what they could do together. They got back to us in a couple of weeks saying they had had a great time thinking about what could help. They had a bird table and bench a watercolour set so they could both learn to paint. Some pots and pans as they going to get better at cooking and a new rug to make the front room look nice. 'thinking about nice things gave us hope for the future' CL 10595 £394
- ❖ A father lives with his 12 year daughter with severe physical and mental difficulties. He had heard about our project and wondered if we could help him with somewhere for his daughter to lay without having to be strapped in. He told us that the only place she can lay free is on the bathroom floor. So he sits on the toilet every day for some time to give her this time. He had researched and found a large purpose built bean bag that she could lay on anywhere in the house. They can then could have quality time, both being comfortable. They chose the colour and fabric and are really pleased with it. CL 8316 £294