

Healthy

PARENT CARERS

Plain English Research Summary

What aspects of health and wellbeing are most important to parent carers of children with disabilities?

Key Points

- Programmes like Healthy Parent Carers try to help parent carers with their health and wellbeing. They often use questionnaires to show that they work.
- Existing questionnaires might not cover the aspects of health and wellbeing most important to parent carers.
- We interviewed 30 parent carers and looked carefully at their responses.
- Parents talked about three big themes. In the 'self, identity and beliefs' theme, they told us that they almost always see themselves as parent carers – and only as parent carers. This can have a negative effect on health and mental wellbeing.
- The 'social connections and support' showed us that parents are isolated and lonely a lot of the time – even when they spend time with people who are not parent carers.
- The 'health-promoting practices and outcomes' theme showed us that there are things parents can do to help them feel better. However, parent carers often have very little free time and feel tired a lot the time.
- Questionnaires which focus on what parent carers talked about in our study might be a better choice than existing questionnaires for researchers who want to show that their programme works.

Who did the study and why?

Researchers like those at [PenCRU](#) are aware that parents of children with disabilities have it tough. They are under more financial pressure and experience more stress. They also get to spend less time with friends and work colleagues, making them feel isolated. Unsurprisingly, these issues have a negative effect on their physical health and mental wellbeing.

There are programmes like Healthy Parent Carers that try to help. However, to get people to join a programme like this, or to get it funded, the organisers need to prove that it makes a difference. One way to do this is by using questionnaires. It works like this: you measure health and wellbeing before the programme, then you measure it again after doing the programme. If there has been a positive change, you can claim the programme works!

Unfortunately, when existing questionnaires have been used, they haven't really captured these positive changes – even when parents say they feel better...

As a research team, discussed this and spoke to parent carers. We learned that existing questionnaires probably don't measure the bits of health and wellbeing most important to parent carers. That's why, for this project, we asked them:

- Which challenges do you face which have an impact on your health and wellbeing?
- Which bits of health and wellbeing should be measured to show things have got better?

What did we do?

We interviewed 30 parent carers using a "topic guide". To make sure the topic guide asked the right questions, we checked with a group of parents who have knowledge of being parent carers because that is crucial knowledge that we don't have.

We got the interviews written up and read each of them a few times, all the while looking for patterns because we wanted to know whether certain themes came up for lots of the parents interviewed.

What did we find?

Parents talked about three big themes. The first one was called 'self, identity and beliefs'. It told us that parent carers almost always see themselves as parent carers first, and as sons, daughters, husbands and wives second. This is exhausting, because being a parent carer is a highly responsible and stressful job.

Still, if parent carers get chances to 'feel like their old selves' or find new ways to explore different aspects of themselves, then they may feel happier and healthier.

The second theme was called 'social connections and support'. This theme said that parent carers are isolated and lonely a lot of the time. Even when they spend time with other people, if these people don't 'get it' like other parent carers do, then they still feel lonely. However, the good news was that when parent carers did get to spend time with people who 'get it', then they can feel more connected and less alone.

The final theme was called 'health-promoting practices and outcomes.' This theme was much more about the things parents can do to help them feel better. Many parents talked about having very little free time and being tired all the time. But – when they were able to find a little bit of time for self-care, gentle exercise and a bit of rest – the positive difference was massive.

What's next?

Happy and healthy parent carers are those that: feel like they do a good job, get to spend time with people outside of their immediate family, and feel more in control of their lives. Questionnaires which focus on these things would be a better choice for researchers who want to prove that their programme works.

Additional Information

The full version of this research paper is published in the journal *Health Expectations*. It was first published on 6th June 2024. If you would like a copy, please contact pencru@exeter.ac.uk

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