



# An exploration of emotional wellbeing in parent carers

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## Aims and Purpose

Despite the well documented additional stressors on parents of disabled children (parent carers) most still manage to look after their emotional wellbeing. As a parent carer myself I wish to promote the parent carer voice to the centre of research and policy. This study utilises the lived experience of parent carers to determine factors that help attain, maintain and support their wellbeing.

Building on Ryff's<sup>[1]</sup> definition of wellbeing: self-acceptance; purpose in life; positive relations with others; environmental mastery; personal growth and autonomy, the aim of this study is to provide information, advice and a framework to guide other parents, professionals, services and future research.

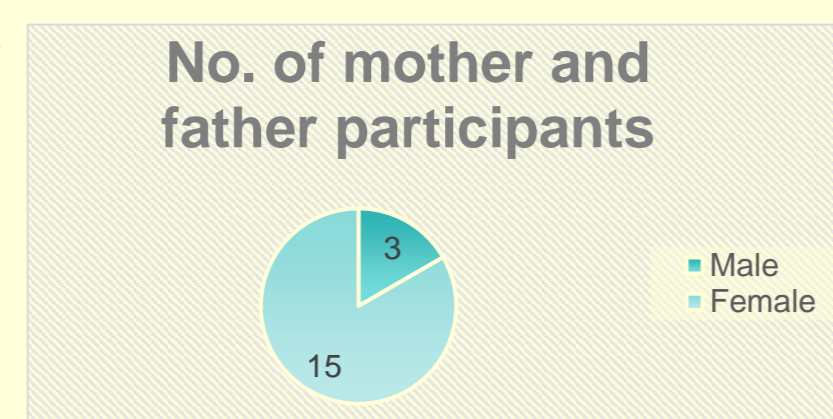
Feeling de-skilled is an understandable reaction to an unexpected situation and this can be exacerbated when life becomes full of 'experts'. Acknowledging the inherent power imbalance in research I am open about being an insider researcher aiming to be a 'steward of stories'<sup>[2]</sup> rather than a recipient of data.

## Design Methodology

This is an interpretive phenomenological qualitative study underpinned by pragmatism and the importance of making research matter<sup>[3]</sup>. Analysis is ongoing using Template Analysis<sup>[4]</sup>.

Parent carers were recruited using various online platforms. The criteria was:

- Parent of a child with a learning and/or developmental disability
- Child aged between 2-11
- Primary caregiver
- At least 2 years since diagnosis



Recruitment was challenging. I therefore increased the upper age of the child. I conducted 18 face-to-face or online semi-structured interviews.

Six tentative (and overlapping) themes have been developed so far. These will continue to be clarified. This poster focuses on a single theme: Parent Empowerment.

## Theme 1: Empowerment

Parent carers commonly reported that feeling empowered had a positive affect on their wellbeing. Empowerment enables people to 'gain control over their destinies'<sup>[5]</sup> and encapsulates two aspects of Ryff's wellbeing – autonomy and environmental mastery. It is a multi-faceted concept: a process and an outcome, functioning at individual and collective levels as the personal becomes political<sup>[6]</sup>.

Factors that supported parental empowerment included:

- **Collaboration, consultation and equality** with professionals: Parent's voice and opinions are **heard** and **valued**

*'I need to feel that I'm somewhere near the top of the decision-making tree'*

- Becoming more **assertive** and learning to say 'no'

*'You need to be able to say no. Because these people are just doing their job but this is your life.'*

*'I've come to the conclusion I don't have to defend or justify my parenting for anybody.'*

- A sense of **connection with others** in a similar situation

*Realising 'there's a whole back drop there to fight your corner with you.'*

- Having a **'map', plan or sense of direction.**

- This may be from gaining knowledge and skills either from parent's own research or through appropriate, trustworthy and compassionate external support:

*'For me, it's always about training and getting an understanding and then feeling empowered'*

- It may be from gaining a **diagnosis:**

*'Once I had the diagnosis, it gave me something to protect me and my son'*

- Or using **prior skills and experience:**

*'That's always been my life's work, being a bridge to helping people to understand how to beat the system, if you like.'*

Other parents were empowered through work, other activities away from their child or small achievements that gave them 'quick wins'.

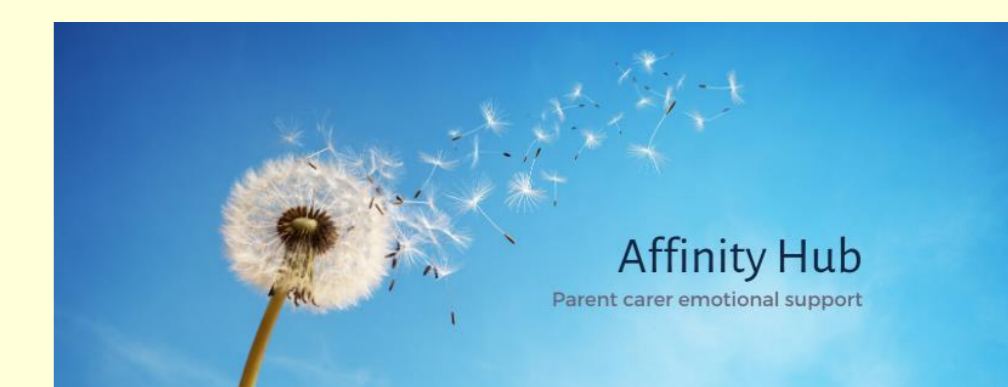
## Discussion

Parents can identify factors that support their emotional wellbeing. However, a considerable focus of the interviews were on factors that did not help the parent. This reflects the 'see-saw'<sup>[7]</sup> nature of wellbeing and that adaptation is not necessarily the 'absence of stress or other negative feelings'<sup>[8]</sup> I refer to this as 'Charmolypi', a Greek word meaning happiness and sadness intermingled<sup>[9]</sup>. This phenomenon is illustrated throughout the themes.

**Limitations:** The findings of this research must be considered in light of the small and limited sample.

### Next steps:

- Continue to analyse the rich data and clarify themes
- Write guidance for professionals and services, parents (a book due to be published 2021) and academic paper
- Continue to share information and advice through my website [www.affinityhub.uk](http://www.affinityhub.uk) and related social media to ensure the research is accessible and directly relevant to peoples' lives



## References

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