

CO-ASSIST: Plain English Summary of the Findings

Aims

To lay the foundation for a parent-focused strategy to improve support for parents/carers of children with OCD.

Background

Caring for a child with OCD can be extremely difficult. Parents and carers often feel unsupported, and it is unclear what support is best.

Methods

Phase 1

We spoke to parents and professionals to understand the needs and challenges when caring for a child with OCD. We looked at published evidence on support for parents of children with a range of mental health conditions, such as anxiety and depression.

Phase 2

We combined learning from phase 1 to produce a roadmap of potential support strategies. Parents and professionals discussed and voted on these strategies to help us decide which were most helpful, while also being feasible to provide.

Phase 3

Parents and professionals reviewed results from the phase 2 voting to select the components of a support package and how these might be delivered.

Findings

The most workable, helpful solution to address this gap in provision was an online platform containing sensitive parent-informed resources and information to i) support and equip parents to support their child ii) help parents make sense of OCD iii) support parents to develop a shared understanding of OCD within the family iv) help parents to consider their self-care v) provide opportunities for parents to be heard by people who understand. Getting the right help at the right time for their child and dispelling misconceptions around OCD were also identified as requiring wider organisational and public health initiatives.

Patient and Public Involvement

A parent co-researcher and senior representatives from two national service-user led charities, contributed to all stages of the research project.

Sharing outputs and impact

We will publicise findings from CO-ASSIST through an animation, podcast, and plain English summary, together with the publication of academic articles. All outputs will be shared widely through social media and national charities.

Conclusions and future plans

There is a pressing need to develop and test the online support platform for parents and carers of children with OCD. We are seeking funding to achieve this.

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