

CO-ASSIST - Plain English Summary

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.

Phase 2

We combined our learning with published evidence to produce a roadmap of support strategies. Parents and professionals discussed and voted on these strategies to help us decide which are most helpful while also being feasible to provide.

Phase 3

Parents and professionals reviewed phase 2 voting to identify 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 Chief Executives of two national service-user led charities contributed to all stages of the research project.

Dissemination outputs and impact

We are raising awareness by sharing a podcast and plain English summary through social media and charity channels, together with the publication of articles.

Conclusions and future plans

There is a pressing need to develop and test this online intervention. We are seeking funding to achieve this