



CEREBRA

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## **FINAL PROGRESS REPORT FORM**

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**1. GENERAL INFORMATION**

<b>PROJECT TITLE</b>
Online and virtual psychological wellbeing interventions for family carers of people with Intellectual and Developmental Disabilities: A systematic review.
<b>APPLICANT/S</b>
Dr Jo Griffin, Dr Samantha Flynn (JG and SF were joint lead applicants), and Professor Richard Hastings
<b>ORGANISATION</b>
University of Warwick
<b>REPORT DATE</b>
20 <sup>th</sup> March 2024
<b>REPORT PERIOD</b>
(September 2022 – March 2024)

**2. BACKGROUND INFORMATION**

Provide an introduction that reviews the context and rationale for your research.
<p>Parents of people with intellectual and developmental disabilities are often at increased risk for stress and mental health problems and may face more challenges than other carers as they have a higher caring load, more financial struggles, a more negative impact of caring on their personal life, and overall poorer health (e.g., disturbed sleep, feeling depressed) when compared with other carers. Throughout this report, we will be using the broad term “psychological wellbeing” to refer to mental health problems such as anxiety and depression, stress, and positive measures of well-being.</p> <p>Despite awareness that family carers of people with intellectual and developmental disabilities often have poorer wellbeing than other carers, psychological supports directly targeting the psychological wellbeing of parents of individuals with intellectual and developmental disabilities have rarely been tested robustly in research.</p> <p>Digital delivery of psychological wellbeing interventions might offer a flexible solution to challenges faced by family carers in attending face-to-face sessions (e.g., childcare, transport, health problems), but it is not widely understood what interventions are being used with family carers of people with intellectual and developmental disabilities, how effective they are, what family experiences are, and what factors affect successful implementation.</p> <p>This review aimed to synthesise the literature, provide recommendations for future research directions, and develop recommendations about virtual and online psychological wellbeing interventions that appear to be effective for families of people with intellectual and developmental disabilities, with wider policy and practice implications.</p>

### 3. PROGRAMME SUMMARY

#### ORIGINAL AIMS AND OBJECTIVES (AS GIVEN IN YOUR APPLICATION)

We aimed to complete a systematic review of the literature on virtual and online psychological wellbeing interventions for family carers of people with intellectual or developmental disabilities.

There were four objectives for this study, and these were:

1. To summarise what virtual and online psychological wellbeing interventions for families of people with intellectual and developmental disabilities have been reported in the international research literature.
2. To synthesise the evidence for the effectiveness of virtual and online psychological wellbeing interventions for families of people with intellectual and developmental disabilities.
3. To describe the experiences of families of people with intellectual and developmental disabilities receiving virtual and online psychological wellbeing interventions.
4. To synthesise the evidence about the implementation of virtual and online psychological wellbeing interventions for families of people with intellectual and developmental disabilities, including factors that affect successful implementation.

#### HAVE YOUR AIMS AND OBJECTIVES CHANGED? IF SO, EXPLAIN IN WHAT WAY AND WHY

No. The aims and objectives remained the same.

#### SUMMARY OF OUTCOMES

The study delivered fully against the intended objectives.

To do this, we developed and registered a protocol for the systematic review prior to any searches commencing. The protocol detailed our approach to conducting the searches, defined our search terms, and outlined our proposed methods of data synthesis.

We developed four sets of search terms about (1) intellectual and developmental disabilities, (2) digital delivery of interventions, (3) psychological wellbeing outcomes, and (4) family carer roles. We combined all of these search terms in our searches of seven databases.

In addition to searching databases, we also undertook forwards and backwards reference searches of included papers, contacted the authors of included papers to identify unpublished or missed literature, and searched the reference list of a recently published review that was interested in a similar area to ours.

Initial screening of the titles, abstracts, and keywords of all retrieved papers were undertaken by one member of the research team, and 20% of these were independently verified by another member of the research team. The agreement rate for initial study selection was 98.29%.

The full texts of all potentially eligible studies from the initial screening stage were independently reviewed by two members of the research team with disagreements being resolved in collaboration with a third member of the research team. The agreement rate for full text inclusion was 97.73%.

Data were extracted from the 23 included papers, and quality appraisals were conducted for all included papers using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018).

Data were synthesised narratively using the research questions as a framework, and was included in the academic paper which is currently in preparation to be submitted to a journal for peer review.

### KEY FINDINGS

- We included 23 studies about 21 virtual and online psychological wellbeing interventions for family carers of people with intellectual or developmental disabilities, synthesising a large amount of data into an academic paper for publication. Further outputs to share the findings and implications of the systematic review are being co-produced with family carers for wider dissemination with family carers and professionals.
- The focus of interventions was broad, with five broad categories: mind-body, relaxation, mindfulness and acceptance, psychoeducation and support groups, positive thinking and self-compassion, spirituality, or expressive writing.
- Only a small number of interventions were co-designed or co-delivered by family carers with clinicians or researchers. This is an area of development for future digital and online interventions.
- Most studies reported positive outcomes for the wellbeing of family carers of people with intellectual and developmental disabilities. Further, two studies found that there were no differences in improvements between the same programme being delivered to family carers online or face-to-face. This finding is promising in terms of the potential impact and utility of online and digital interventions.
- Barriers to engagement and implementation included difficulties with technology, difficulty finding time to engage, information not always being relevant for all members of groups, and digital delivery sometimes preventing meaningful connections being made between group members. Facilitators included the online format which was reported as being better than not receiving support in some studies, co-designing and co-developing interventions with family carers, recording missed sessions, and having flexible and interactive activities/strategies for family carers.

### IMPACT STATEMENT

The findings highlight that:

- Online and virtual delivery of interventions to improve family carer wellbeing can be delivered acceptably to family carers, and can lead to improvements being made in their wellbeing. Additional options to traditional face-to-face support could be made available to family carers, opening up choice for family carers.
- Co-produced and co-delivered interventions were also found to be beneficial, however they were not common. Further efforts should be made to meaningfully involve family carers in co-production and co-delivery. No interventions were solely delivered by family carers, and should be an additional area for exploration in future research and intervention development.
- Barriers and facilitators for intervention implementation and engagement of family carers were varied, highlighting the varying needs and preferences of family carers, which should be considered when offering virtual and online interventions to them. This further reinforces the need for greater variety of evidence-based interventions for family carers to choose from.

Through working closely with our advisory group of family carers, we have been able to ensure that our findings and implications of the research are grounded in the experiences of family carers. Further, to maximise the impact of the project beyond academic audiences, our advisory group are working with applicant Dr Jo Griffin to develop resources to be shared with broader audiences of family carers and professionals (detailed in section 6 – Other outputs resulting directly from work of this grant).

#### 4. PLAIN ENGLISH SUMMARY

Please also provide a summary of the outcomes in lay/simple language (avoiding scientific jargon where possible) including an impact statement.

We successfully completed a **systematic review** of research that tested whether online programmes improved wellbeing of family carers of people with intellectual and developmental disabilities. **Systematic reviews** are used by researchers to find all research papers that have been published about a topic and then to summarise all of the relevant information from those research papers to tell a clear story about the information from all of the research papers so that other people can easily see what research has been done, and what it has found.

We found that there had been 23 studies that had tested whether 21 different digital programmes improved the wellbeing of family carers of people with intellectual and developmental disabilities. Programmes were focussed on: mind-body, relaxation, mindfulness and acceptance, psychoeducation and support groups, positive thinking and self-compassion, spirituality, or expressive writing. Most programmes used video-conferencing, websites, or online chat systems, and some programmes also had some face-to-face or telephone contact with the people delivering the programme. Most programmes were delivered in real-time, in groups, and by a clinician, researcher or trainer. A small number of programmes were co-designed or co-delivered by family carers with clinicians or researchers.

Most research papers reported that the wellbeing of family carers had improved after they took part in the online programmes. Two research papers found that there were no differences in improvements between the same programme being delivered to family carers online or face-to-face. Most family carers said that they had positive experiences taking part in the programmes, and this was because they found time to take part, found it useful, enjoyed the activities, and they liked that it was online. When programmes had some connections with other family carers, either taking part in the programme or delivering it, this was found to be helpful.

Things that stopped family carers from getting as much out of the programmes as they could have included: issues with technology, difficulties finding time to take part, programmes not being long enough, information not always being completely relevant because of the range of experiences in the groups, online delivery meaning that meaningful connections were not always possible. Things that helped family carers to get involved in the programmes included: the programme being online as this was better than not getting any support at all, involving family carers in designing or delivering the programmes, recording missed sessions, and flexible and interactive activities/strategies.

#### 5. PUBLIC INVOLVEMENT

Complete this section outlining patient and public involvement in this research. If there is no involvement, please explain why. Please, also comment on how have the research findings been made available/accessible to lay audiences?

We convened an advisory group of family carers who advised and were actively involved in various elements of the study, from co-authoring the protocol, to supporting the conceptualisation of the data, and co-authoring the systematic review manuscript. Our advisory group are also working with applicant Dr Jo Griffin to develop a series of non-academic outputs (detailed in section 6 – Other outputs resulting directly from work of this grant).

We have had three project advisory group meetings with the whole team and two family carers, and then a further three meetings with applicant Dr Jo Griffin and the two family carers to discuss and agree the additional outputs and record the videos to be dissemination.

## 6. PUBLICATIONS AND OTHER OUTPUTS

### PUBLICATIONS RESULTING DIRECTLY FROM WORK OF THIS GRANT

Apanasionok, M., Paris, A., Flynn, S., Griffin, J., Finch, E., Austin, D., & Hastings, R. (in preparation). A systematic review of digital psychological wellbeing interventions for family carers of people with Intellectual and Developmental Disabilities.

Number of **published or in press** papers: 0

Number of papers **in preparation or submitted**: 1

### OTHER OUTPUTS RESULTING DIRECTLY FROM WORK OF THIS GRANT

The following resources are being developed by applicant Dr Jo Griffin with the advisory group members (Ellie Finch and Debbie Austin) with the intention of sharing the results and key messages from the academic publication with a broader audience:

- An information sheet for parent carers and professionals,
- A brief article for the Cerebra website
- Videos about the findings and experiences of family carers on the advisory group
- An article for the Psychologist magazine, or similar publication

### OTHER PUBLICATIONS/OUTPUTS THAT HAVE BEEN FACILITATED OR SUPPORTED BY THIS GRANT

Griffin, J., Hastings, R., Apanasionok, M., Paris, A., Finch, E., & Austin, D. (2023). *A systematic review of digital psychological wellbeing interventions for family carers of people with Intellectual and Developmental Disabilities (IDD)*. PROSPERO 2023 CRD42023407687 Available from: [https://www.crd.york.ac.uk/prospero/display\\_record.php?ID=CRD42023407687](https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42023407687)

### DISSEMINATION OF RESULTS

Apanasionok, M., Paris, A., Griffin, J., Flynn, S., Austin, D., Finch, E., & Hastings, R. A Systematic Review of Digital Psychological Wellbeing Interventions for Family Carers of People with Intellectual and Developmental Disabilities. Seattle Club Conference, Birmingham, December 2023 (poster presentation).

Preliminary findings were also presented to family carers in our study advisory group in February 2024.

## 7. ADDITIONAL COMMENTS

Please note any additional comments relating to this report or anything that has not been covered in any other section.

N/A

8. DISCLAIMER

**PLEASE NOTE:** An electronic signature is required

I certify that the statements and data included in this report are true, complete and accurate to the best of my knowledge.

Date: 20<sup>th</sup> March 2024

Signature:

Two handwritten signatures in black ink. The first signature is 'J. Griffin' and the second is a stylized signature.