



CEREBRA

Working wonders for children
with brain conditions

FINAL PROGRESS REPORT FORM

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1. GENERAL INFORMATION

PROJECT TITLE
PosFam – A positively-oriented, family systems intervention for families of children with developmental disabilities
APPLICANT/S
Professor Richard Hastings, Dr Samantha Flynn, and Dr Tom Bailey (replaced by Dr Paul Thompson)
ORGANISATION
University of Warwick
REPORT DATE
REPORT PERIOD
January 2021 – December 2023

2. BACKGROUND INFORMATION

Provide an introduction that reviews the context and rationale for your research.
<p>Families of children with a developmental disability (such as an intellectual disability or who are autistic) are at increased risk of psychological and family difficulties. Parents of children with a developmental disability are more likely to report symptoms of mental health problems. Children with a developmental disability and their siblings experience more behavioural and emotional problems. Families of children with a developmental disability on average report more difficulties in family relationships such as poorer family functioning and lower spousal relationship satisfaction. Of course, these difficulties are not universal, but the increased frequency of these challenges highlights the importance of providing support to families of children with a developmental disability.</p> <p>Family-focused interventions, which aim to improve wellbeing and relationships by targeting the interactions between different family members, have been proposed as potentially helpful for families of people with a developmental disability. This is because there is good evidence for the effectiveness of family-focused interventions with many other populations and because many ideas from family-focused interventions appear to be highly applicable with families of children with a developmental disability.</p> <p>There is also a need for positively-oriented support for families of children with a developmental disability. Existing support is typically targeted towards the alleviation of difficulties for families who are particularly struggling. However, as well as experiencing challenges, we know that many families of disabled children often report positive experiences, such as viewing their child as a source of happiness and fulfillment and developing new outlooks or perspectives on life. There are fewer support programmes that aim to promote positive outcomes such as wellbeing and family relationships by seeking to build upon these kinds of positive experiences.</p> <p>A third issue is that programmes designed to support families of people with a developmental disability have often not been developed in partnership with them. Support developed without input from family carers may lack acceptability and fail to address carers' priorities. An alternative approach is co-production, in which researchers and stakeholders work together on a project and meaningfully share power and responsibility. Co-production can be mutually beneficial; offering</p>

researchers a rich source of expertise on the experience of family carers to inform the development of acceptable interventions, and offering family carers a sense of value and the opportunity to use their expertise for a positive purpose.

Determining whether a programme developed to address these needs was effective would require a large-scale randomized-controlled trial. However, several steps are required before this. First, the programme must be developed and piloted. Researchers should then conduct a feasibility study to check that everything might work before proceeding to a large-scale trial. The purpose of a feasibility trial is to assess the viability of conducting a definitive evaluation of an intervention and establish how this may be successfully conducted. An embedded process evaluation examines how an intervention works and how well it can be delivered.

3. PROGRAM SUMMARY

ORIGINAL AIMS AND OBJECTIVES (AS GIVEN IN YOUR APPLICATION)

The research set out to address two main aims:

- i. Co-production with families of children with a developmental disability (intellectual disability and/or autism) to develop a new family systems positively focused programme (Positive Family Connections)
- ii. Carry out an evaluation study, including random allocation and a process evaluation, of Positive Family Connections

Phase 1- co-production and intervention development

In the funding application, we outlined several characteristics that the new programme would have. First, it would be positively-oriented, seeking to build upon families' positive experiences and promote positive outcomes such as wellbeing and family relationships rather than directly targeting negative outcomes. Second, it would be based upon family-systems theory. Third and crucially, it would be co-produced with family carers throughout and be designed to be delivered by trained family carer facilitators.

Phase 2- evaluation of the programme (later named *Positive Family Connections*)

In the funding application, we planned to conduct a feasibility randomised-controlled trial of the new programme with 58-60 families, as well as a process evaluation of the trial. As well as being a preliminary evaluation of the effectiveness of the programme, this project aimed to address the following feasibility questions:

- a. Recruitment of families: What are the most effective pathways to recruit families of children with a developmental disability? What recruitment rate for families can be achieved? What proportion of the recruited sample are mothers, and what proportion are fathers?
- b. Recruitment of family carers to deliver the intervention: Can family carer mentors be recruited and trained to deliver the programme in pairs for the study?
- c. Acceptability of research design: Are families willing to be randomised within the context of a RCT?
- d. Fidelity of implementation: Can family carer facilitators deliver the programme with a high fidelity to the manual?
- e. Adherence: What proportion of parents complete the programme (attending 70%+ sessions)?
- f. Retention: What proportion of parents are retained in the research study to the 9-month follow-up?
- g. Usual support: What interventions do families receive typically? How is this "usual support"

different from the content of the new programme?

h. Feasibility of outcome measures: Do parents complete the outcome measures for the study?

i. Design and methods for future health economic analysis: What is the feasibility of collecting resource use and health related quality of life data for parents and children in the family?

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

No - aims remained the same.

SUMMARY OF OUTCOMES

This research project delivered fully against all the intended objectives.

Phase one- co-production and programme development

We successfully co-produced a new programme with family carers that the family carers and research team jointly decided to name *Positive Family Connections*. The co-production began by recruiting a development group comprised of five family carers (two fathers and three mothers) through networks and existing connections. The development group met virtually (on Zoom) four times and developed the themes, content, and format of the program. Smaller working groups also met between these meetings to work on areas of content in greater detail.

This initial development process resulted in a Logic Model that summarises the content of the programme, its intended outcomes, and the processes by which it aims to produce these outcomes. The draft programme was then piloted by development group members with two groups of seven family carers. Following each session, a research team member (Daniel Sutherland) met with the groups and collected formal feedback about their experiences of the program. These data, as well as the experiences of the group facilitators were used to inform the further refinement of the programme.

The final programme consists of six, two-hour sessions which are designed to be delivered virtually to groups of around six to eight families, with up to two family carers attending from each family. The programme is facilitated by two or three family carer facilitators. The sessions address the following topics:

- 1) Introduction, family systems, positive approach, getting to know the group
- 2) 'Spinning all the plates', 'naming' difficulties, managing time
- 3) Communication, expressing ourselves and active listening
- 4) Noticing – ourselves and others, precious little moments in family life
- 5) Activities – doing things together, celebrating your family's uniqueness
- 6) Bringing it all together, tea party, keeping in touch

Following the development and piloting of the programme, the research team and development group co-authored a peer reviewed paper (Griffin et al., 2023) about the development of *Positive Family Connections*. Whilst writing this paper, we collected feedback from the development group members on their experiences of co-producing the programme. Their responses emphasised that they felt that their contributions were respected and that they valued the opportunity to contribute towards work that might help families of children with a developmental disability.

Phase one was therefore successful in achieving its goal of developing a co-produced, positively oriented, family-systems based programme for families of children with a developmental disability. The key output from this phase is the *Positive Family Connections* programme itself. This includes a manual containing guidance for facilitators as well as materials for the programme such as slides and worksheets. This manual will form the basis for any future research on *Positive Family*

Connections. Dissemination outputs are described later in this report.

Phase two- evaluation of Positive Family Connections

We have also successfully completed a feasibility randomised-controlled trial and process evaluation of *Positive Family Connections* as proposed in the original grant application.

Methods

Study design

The study was a waitlist controlled, feasibility cluster randomized-controlled trial (with clusters being families consisting of one or two participating family carers). Participants were randomly allocated to either be invited to *Positive Family Connections* straight away or to wait to be offered the programme later. The protocol was preregistered prior to the trial being carried out (ISRCTN 14809884).

Recruitment

We aimed to recruit 60 families with up to two carers participating from each family. Primary parental carers were recruited through social media and Cerebra's newsletter and contact database. A researcher assessed primary parental carers' eligibility, and if they were eligible, they could invite a second family carer to consent independently to take part in the study.

Participants were adult family carers of a child with a developmental disability aged 8-13 years. The primary parental carer was the person that the child lived with most of the time. Second family carers could be any adult identified by the primary parental carer that they considered to be a part of their family. All family carers needed to be aged ≥ 18 years.

Randomisation

Families were randomly allocated by a statistician to take part in *Positive Family Connections*, or to a waitlist condition to be invited 12-months later to take part in the programme. If two family carers from a family took part, they were allocated as a cluster.

Measures

The proposed (and so pre-defined) primary outcome measure for a future trial was the family APGAR scale, a brief measure of family functioning. We also collected secondary outcome data relating to: carer psychological wellbeing, carer psychological distress, carers' positive perceptions of their family member with a developmental disability, behavioural and emotional difficulties in the family member with a developmental disability and a sibling, sibling relationship quality, parent-child relationship quality for the family member with a developmental disability and a sibling, carers' relationship satisfaction and parenting disagreements, support from and conflict with grandparents, and the health-related quality of life of carers, the child with a developmental disability, and a sibling. We also collected data on the health and social services that families accessed to assess the feasibility of a conducting a health-economic (i.e., cost-effectiveness) analysis in a future trial.

Qualitative interviews

We collected qualitative data to understand participants' and facilitators' experiences of taking part in the study and the *Positive Family Connections* programme. We interviewed all nine of the facilitators that delivered the programme, eight participants who were allocated to take part in

Positive Family Connections straight away, and eight participants who were invited to take part in *Positive Family Connections* 12-months later. These interviews were conducted virtually, transcribed, and analysed using a structured approach called Framework analysis.

Findings

Objective 2a- assessing recruitment of families

Participants were recruited between 20 February 2022 and 09 May 2022. 101 people initially expressed interest in participating. Of these, 72 completed an eligibility assessment and 67 were eligible. Ultimately, 60 primary parental carers and 13 second family carers took part in the study. We therefore successfully achieved our recruitment target. In interviews, participants' main motivations to take part related to the desire to contribute towards research they viewed as valuable and important, and hoping the programme would be beneficial for themselves and their family. Where participants identified potential barriers to participating, these typically related to the time demand and the feasibility of attending the group alongside other commitments. However, these were generally mitigated by the choice of groups at appropriate times, and funding of childcare when required.

Objective 2b- assessing recruitment and training of facilitators

Nine family carer facilitators were successfully recruited and trained to deliver *Positive Family Connections* in the trial. Facilitators were recruited from members of the *Positive Family Connections* development group (n=4), pilot group participants who had taken part in a *Positive Family Connections* group themselves (n=3), contacts of the research team (n=1), and contacts of development group members (n=1). Facilitators gave varied motivations for their involvement including: the opportunity for paid work, trying something new, supporting family carers, and being attracted by the fact that the programme being delivered by family carers.

Objective 2c- acceptability of research design

The nature of the random allocation to either take part in *Positive Family Connections* straight away or to be invited 12-months later was clearly explained to participants during recruitment. The research design appeared to be acceptable to participants, as evidenced by our recruitment data (59.41% of participants who expressed interest ultimately took part in the study) and no participants withdrawing after randomisation. Interviewed participants also generally described feeling satisfied with the research design so long as this was clearly explained to participants during recruitment.

Objective 2d- fidelity of programme delivery

To assess whether facilitators delivered the programme with a high level of fidelity (i.e., according to the manual – note that the manual also includes significant flexibility to respond to families' needs throughout delivery), facilitators completed a checklist following each session to report whether each component was covered, partially covered, or not covered. Programme fidelity was high overall. Across all four groups run for the trial, facilitators reported that 94.02% of programme components were delivered (range = 92.26% to 99.12%), 2.99% partially delivered, 2.72% not delivered, and 0.27% were not reported. This suggests that trained family carer facilitators can deliver the *Positive Family Connections* programme in accordance with the manual and that the planned content can be delivered within the time set aside for six sessions.

Objective 2e- adherence

We assessed participants' adherence to the programme by collecting data on participants' attendance at each session. We agreed beforehand that we would consider a family to have

completed *Positive Family Connections* if they attended four or more sessions. In the intervention group, 73.33% of primary parental carers and 71.43% of second family carers attended four or more sessions. Primary parental carers attended an average of 4.03 sessions. Second carers attended an average of 4.14 sessions. Whilst attendance was difficult for some families, as would be expected, the majority of families were able to complete the programme. Interviewed participants reported missing sessions generally due to unavoidable commitments such as medical appointments.

Objective 2f- retention

We had excellent levels of retention in the study. At 4-month follow-up, 98.33% of primary parental carers and 92.31% of second carers provided at least some follow-up data including the proposed primary outcome of the family APGAR. At 9-month follow-up, 98.33% of primary parental carers and 100% of second carers provided at least some follow-up data including the family APGAR. Retention remained high for all secondary outcomes. For primary parental carers, the percentage of data collected for secondary outcomes ranged from 89.36% to 96.67% at 4-month follow-up and 91.38% to 95% at 9-month follow-up. For second carers, the percentage of data collected for secondary outcomes ranged from 69.23% to 92.31% at 4-month follow-up and 83.33% to 100% at 9-month follow-up. In interviews, participants expressed being motivated to complete the follow-up surveys by the offer of vouchers and the opportunity to contribute to research that they viewed as important.

Objective 2g- usual support

To assess what usual support families received, we collected data on the health and social care services that they had accessed in the previous three months for either themselves or their family member with a developmental disability. At baseline, 30 participants had contact with their GP and small numbers had contact with other services including counsellors (n=3), social workers (n=2), and a family support worker (n=1). Almost one third of participants took psychotropic medication (n=18) such as SSRIs, tricyclics, benzodiazepines, or SNRIs. Only two participants reported accessing peer support groups and these were delivered through a parent carer forum or their child's school. The lack of access to programmes or other support similar to *Positive Family Connections* suggests that in a future study a comparison with usual support would be feasible.

Objective 2h- feasibility of outcome measures

There were very few missing items within returned questionnaires. Interviewed participants generally described the questionnaires as not being too burdensome. Gathering outcome data, therefore, appears to be feasible for use in a future trial.

Objective 2i. Design and methods for future health economic analysis:

Conducting a health-economic analysis looking at the cost-effectiveness of an intervention requires data on participants' health-related quality of life and the support that they access before and after receiving the intervention. We did not propose to conduct a health-economic analysis in this study, but we did assess the feasibility of collecting the necessary data in a future trial. Data required for a future health-economic evaluation were successfully collected from most participants. Resource use data on health and social service use were obtained for 98.33% of primary parental carers and 91.67% of carers reporting on their children at baseline and 86.67% of both primary parental carers and children at 9-month follow-up. Data on health-related quality of life were fully completed for 98.33% of carers at baseline, 90.41% of carers at 4-months, and 91.78% of carers at 9-months. Health-related quality of life data were completed for 100% of children at baseline, 91.67% at 4-months, and 91.67% at 9-months and 97.87% siblings at baseline, 91.49% at 4-months, and 100% at 9-months.

Preliminary evaluation of the effectiveness of *Positive Family Connections*

Since this project was a feasibility study, it did not have sufficient sample size to definitively evaluate the effectiveness of *Positive Family Connections*. However, we conducted a preliminary analysis of whether *Positive Family Connections* may be beneficial. This involved analysing the changes in questionnaire outcomes between baseline, 4-month follow-up, and 9-month follow-up and between those families that were allocated to take part in *Positive Family Connections* straight away and those that were allocated to be invited 12-months later. These main analyses were conducted on an intention-to-treat basis. This means that all participants' data were analysed, including participants who were allocated to take part in *Positive Family Connections* but who ultimately attended few or no sessions of the programme.

The proposed primary outcome for a future trial was the family APGAR scale which is a brief measure of family functioning. We found that at 9-month follow-up, the *Positive Family Connections* group did not show evidence of improvements in family functioning in comparison to the control group. However, 19.18% of participants scored 10 out of 10 on the family APGAR at baseline and this ceiling effect could potentially obscure the positive impact of *Positive Family Connections* for some participants.

Another outcome of particular interest was the Warwick-Edinburgh Mental Wellbeing Scale, a measure of parents' psychological wellbeing. *Positive Family Connections* did appear to be associated with meaningful improvements in psychological wellbeing at 9-month follow-up when compared with data from the control group. Overall, the majority of secondary outcomes (19/26) favoured the *Positive Family Connections* trial arm (i.e., outcomes were better at the 9-month follow-up for those who were allocated to the *Positive Family Connections* trial arm). Thirteen of these outcomes showed differences that might be considered potentially clinically meaningful (i.e., large enough to be important in practice if replicated in a larger later trial).

As discussed, the main analysis included all participants, regardless of adherence to the *Positive Family Connections* programme. We conducted secondary analyses looking at whether outcomes were different when we only included participants who completed four or more sessions of the programme. These analyses were conducted only for family functioning and family carers' psychological wellbeing. We found that adherence to the *Positive Family Connections* programme was not associated with better family functioning outcomes. However, the improvements in psychological wellbeing were larger amongst participants who completed four or more sessions of the programme. This is a promising sign that actively attending the programme may help to improve carers' wellbeing.

Experiences of the *Positive Family Connections* programme

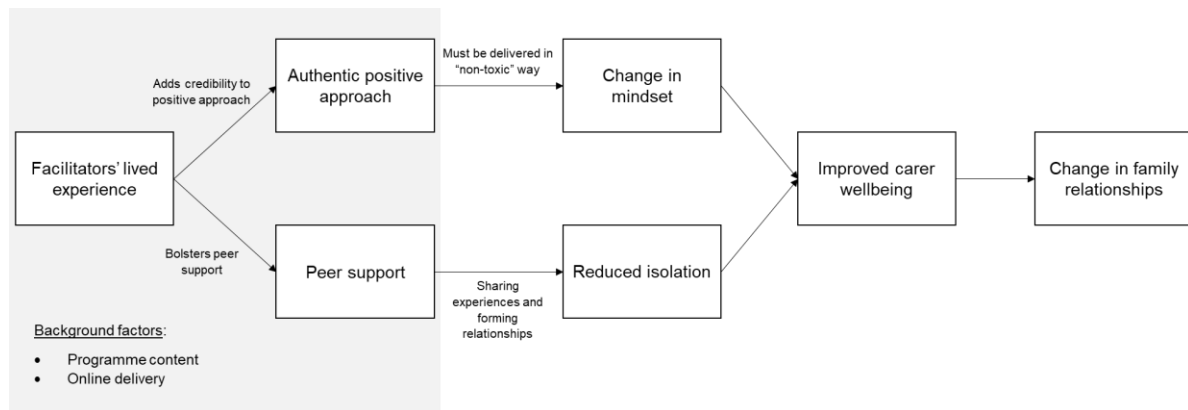
We are currently completing the final steps of analysing the qualitative data on participants' and facilitators' experiences of the *Positive Family Connections* programme. This analysis focuses on understanding the processes through which an intervention is helpful, and why it does or does not succeed in achieving its intended outcomes.

Participants generally described very positive experiences of the programme. Participants particularly valued that the programme was delivered by facilitators who were themselves family carers, having the opportunity to interact with others who had shared experiences, and found the positive approach of the programme distinctive and helpful. When asked about whether they had gained anything from the programme, participants described feeling calmer, less isolated, thinking differently about their experiences, and experiencing positive changes in family relationships.

Facilitators spoke positively about their experiences delivering the programme. They valued the

opportunity to support and learn from other family carers and the importance of having people with lived experience delivering the programme. Facilitators similarly valued the positive approach of the programme, although they worked hard to ensure this was not delivered in a “toxic positivity” way. Sometimes, it could be challenging for facilitators to support participants who were struggling or distressed; highlighting the importance of assessing participants’ suitability/readiness for the programme before they begin.

Based on the qualitative data, we have developed a preliminary model of how the programme might lead to positive changes for participants:



Within this model, the lived experience of facilitators: a) adds credibility to the programme’s positive approach since it is being delivered by individuals who understand carers’ experiences; and b) bolsters the peer support function of the programme since facilitators sharing their own experiences helped the group to bond and become comfortable with one another. The positive approach of the programme was generally viewed as effectively balancing the value of seeking to recognise and build upon positive experiences, whilst not drifting into unhelpful “toxic positivity”. Participants described the positive approach as leading to a shift in mindset in which they recognised more positive experiences and worried less about things that were out of their control. The peer support participants gained from the opportunity to interact and build relationships with other carers in the groups was described as reducing participants’ isolation and strengthening their support network. These two key processes: the change in mindset and reduced sense of isolation then appeared to lead to improvements in carers’ wellbeing, for example describing feeling less stressed and like they were calmer parents. These changes in carers’ own psychological wellbeing then in turn appeared to lead to changes in family relationships, such as viewing their family more positively, and spending more quality time together. This model is preliminary, and may be revised following finalising the qualitative analysis. However, these findings indicate that participants and facilitators generally had positive views of the programme and the findings help us to better understand how the programme may produce change (that can inform future refinement and delivery). The mechanisms identified were also a close match with the programme theory and logic, suggesting that *Positive Family Connections* generally works as intended.

KEY FINDINGS

Please outline key findings that highlight the significance of this research and its implications for the health outcomes and wellbeing of children living with brain conditions.

- We successfully co-produced a new programme (*Positive Family Connections*) that aims to enhance family relationships and wellbeing in families of children with a developmental disability.

- We have demonstrated that a full-scale randomised-controlled trial of *Positive Family Connections* would be feasible, laying the groundwork for future research.
- Provided preliminary evidence that *Positive Family Connections* may lead to improvements in carers' psychological wellbeing, different aspects of family relationships, and other family members' wellbeing.
- Participants generally had positive experiences of the *Positive Family Connections* programme and qualitative data have indicated that *Positive Family Connections* works in the ways intended.
- These findings support a strong case for a larger-scale randomized-controlled trial of *Positive Family Connections*. If a larger trial were to have positive outcomes, this could lead to the programme being considered "evidence based" with a chance of being implemented on a larger scale to improve family relationships and wellbeing for families of children with a developmental disability in the UK and internationally.

IMPACT STATEMENT

How will the outcomes contribute to the current scientific field, health/social policy and/or the provision of health services? To what degree are these findings being translated into tangible and actionable steps? Who will benefit?

We have successfully co-produced a novel programme with family carers of children with a developmental disability. The success of this co-produced work may help to stimulate further co-production work between researchers and carers and act as a model for similar work. Indeed, this has already begun to occur, with the findings from the *Positive Family Connections* project supporting a successful grant application by Dr Griffin and Professor Hastings for a project developing guidelines for co-production between family carers and researchers. Furthermore, the development of *Positive Family Connections* addresses the lack of family support programmes for families of children with a developmental disability (as identified in our recent systematic review – Sutherland et al., 2023).

This project has also demonstrated that a larger-scale trial of *Positive Family Connections* would be feasible in the future. The very promising feasibility outcomes that we identified suggest future research is possible and would enable a strong grant application for a large-scale trial of *Positive Family Connections*.

We have also provided preliminary evidence that the program may be beneficial. Exploratory statistical analysis showed evidence of improvements in psychological wellbeing and family relationships. Qualitative evidence suggests that the programme is generally acceptable, that participants enjoyed taking part, and experienced benefits.

This project has, therefore, fully achieved its aims to lay the groundwork for a definitive evaluation of *Positive Family Connections* through developing the programme, establishing a trial is feasible, providing evidence for preliminary benefits, and evidence that family carers perceive the programme positively. Were a larger scale trial to find that the programme was effective, safe, and cost-effective, this could lead to the programme being implemented more widely and thereby improve wellbeing and family relationships in families of children with a developmental disability.

We have also sought to maximise the impact of the project through dissemination to broader audiences of family carers and others (see outputs section). These efforts help to communicate the value of research to family carers, and may generate interest in co-production or further research involvement for some carers.

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 created a new support programme for families called *Positive Family Connections*. A group of family carers worked with researchers to develop the themes, content, and format of the new programme. The programme was then piloted (tested on a small scale) with two groups of seven family carers and their feedback was used to improve the programme.

Positive Family Connections involves six, two-hour sessions which are designed to be delivered virtually to groups of around six to eight families, with up to two family carers attending from each family. The programme is run by two or three family carer facilitators. We then completed a **feasibility randomised controlled trial** and **process evaluation** of *Positive Family Connections*. A **randomised controlled trial** is where participants are randomly allocated to either take part in the programme, or to a control group who carry on with their usual supports. Comparing the results between these groups helps researchers learn whether a new programme is helpful. A **feasibility randomised controlled trial** is a research study that aims to look at whether a full-scale trial would be possible and how this could best be designed. A **process evaluation** aims to understand *how* an programme is helpful and understand why a programme did or did not do what it was designed to do.

We successfully conducted a feasibility randomised controlled trial with 60 families. The trial found very positive findings for all of the feasibility questions we had (such as could we recruit families to take part, would they complete study questionnaires, could the programme be delivered as intended). This suggests that a full-scale trial of *Positive Family Connections* would be feasible in the future. We also found preliminary evidence that the programme leads to beneficial effects on family relationships and family carers' psychological wellbeing. Finally, the preliminary findings from the process evaluation suggest that the programme was delivered successfully, that participants generally had positive experiences, and the research has provided a better understanding of how the programme leads to positive change.

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?

Please involve patient or public contributors in completing this and other sections of the progress report.

Co-production with family carers was central throughout the *Positive Family Connections* project. The *Positive Family Connections* programme was co-produced with family carers throughout. As described, a development group of family carers worked with researchers to develop the content of the programme, and *Positive Family Connections* is delivered entirely by trained family carer facilitators. Family carers from the development group co-authored a paper on the development of *Positive Family Connections* which has been published in the *Tizard Learning Disability Review*.

When we interviewed participants and facilitators from the feasibility study, the involvement of family carers was perceived as extremely valuable. Some facilitators and participants were attracted to the study by the fact that the programme was developed and delivered by family carers with lived experience. Participants thought that the programme being delivered by family carers helped to make the programme more credible and relatable.

At the end of the feasibility study, we organised an in-person gathering of researchers and family carers from the development group or who were facilitators. During this meeting we shared the findings from the project and invited family carers' feedback on the experiences of working on the study, the study findings, and outstanding questions that remained to be addressed. Their perspectives have helped to shape the possible design of a future large-scale trial of *Positive Family Connections*.

Family carers were also involved in disseminating findings from the project. For example, family carer facilitators have recorded videos for Cerebra sharing their experiences of co-producing the programme and sharing the findings from the project.

6. PUBLICATIONS AND OTHER OUTPUTS

PUBLICATIONS RESULTING DIRECTLY FROM WORK OF THIS GRANT

List of papers (**published, in press, in preparation or submitted**) resulting **directly** from the work of this grant. **Do not** include publications that are **unrelated** to the research funded through this grant. Please use the following format - Lead author(s), publication title, journal name, year published, DOI/PMID and specify whether each paper is published, in press, in preparation or submitted.

Published/in press papers:

Griffin, J., Austin, D., Lynham, J., Hafidh, R., Boxill, N., Sutherland, D., Flynn, S., & Hastings, R. (2023). Positive Family Connections: Co-producing a virtual group programme for family carers of children with learning disabilities or who are autistic. *Tizard Learning Disability Review*, **28**, 61-70. <https://doi.org/10.1108/TLDR-03-2023-0008>

Sutherland, D., Griffin, J., Flynn, S., Thompson, P., Hastings, R. P. (in press). Positive Family Connections for families of children with a developmental disability: Cluster randomized controlled trial. *Journal of Family Psychology*. doi not yet available

One further paper is in preparation:

Sutherland, D., Griffin, J., Flynn, S., Hastings, R. P. (In preparation). Participant and facilitator experiences of Positive Family Connections for families of children with a developmental disability.

Number of **published or in press** papers: 2

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

OTHER OUTPUTS RESULTING DIRECTLY FROM WORK OF THIS GRANT

For example, contributions to guidelines or policies, or technologies, tools, databases or other resources created.

Positive Family Connections facilitator guide.

Griffin, J., Hastings, R. P., Austin, D., Boxill, N., Burchell, K., Flynn, S., Hafidh, R., Lynham, J, Sutherland, D. *Positive Family Connections Facilitator Guide.*

Trial protocol registration

Sutherland, D., Griffin, J., Flynn, S., Thompson, P., Hastings, R. P. (2022). ISRCTN14809884: Positive Family Connections: an intervention for families of children with developmental disabilities: a feasibility study. <https://doi.org/10.1186/ISRCTN14809884>.

Special Needs Jungle article

Challenging society's negative narrative to understand the positivity of caring for a child with disabilities. <https://www.specialneedsjungle.com/challenging-societys-negative-narrative-understand-positivity-caring-child-disabilities/>

Cerebra articles and videos

<https://cerebra.org.uk/what-we-do/research/our-research-partners/university-of-warwick/positive-family-connections/>

<https://cerebra.org.uk/research/positive-family-connections/>

<https://cerebra.org.uk/research/positive-family-connections-latest-news/>

Cerebra videos on co-production and findings currently in development

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

Please list any other publications or outputs that have been indirectly supported by this grant, indicating for publications whether they are in preparation, submitted, in press or published.

Sutherland, D., Flynn, S., Kurzeja, O., Griffin, J., & Hastings, R. P. (2023). Family-systems interventions for families of people with an intellectual disability or who are autistic: A systematic review. *Journal of Intellectual Disability Research*, **67**, 1003-1028.

<https://doi.org/10.1111/jir.13068>

DISSEMINATION OF RESULTS

List where and by whom your findings have been disseminated. This may include conferences and workshops, but may also include other engagement events, for example related to patient & public involvement.

Project findings were presented to family carers involved in developing or delivering *Positive Family Connections*. October 2023.

The research team also gave the following conference presentations at academic and family carer conferences:

Sutherland, D., Griffin, J., Flynn, S., Thompson, P., Hastings, R. P. (2023). Positive Family Connections: a feasibility randomised-controlled trial of a co-produced family systems intervention. 20th Seattle Club Conference on Research in Intellectual Disabilities. Birmingham, UK.

Sutherland, D., Griffin, J., Flynn, S., Thompson, P., Hastings, R. P. (2023). Positive Family Connections: a feasibility randomised-controlled trial of a co-produced family systems focused intervention. 14th European Congress of Mental Health in Intellectual Disability. Helsinki, Finland.

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7. ADDITIONAL COMMENTS

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

NA

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: 24 January 2024

Signature: 