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Tizard Learning Disability Review

Positive Family Connections: Co-producing a virtual group programme for family carers of children with learning disabilities or who are autistic

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Abstract

Purpose: This paper outlines the process of developing a new co-produced virtual group support programme called Positive Family Connections aimed at family carers of children with a learning disability, or who are autistic, aged between 8-13 years.

Development Process: Family carers were recruited to develop Positive Family Connections prior to a feasibility randomised controlled trial being conducted (not reported in this paper). The programme was positively oriented and family-systems-focused. Positive Family Connections was developed by family carers, along with the research team, and designed to be delivered by family carer facilitators. The development process included several meetings to design the format and content of the programme. An initial pilot was then delivered and further amendments made to the programme in response to the pilot participants' feedback.

The programme: The co-produced Positive Family Connections (PFC) programme involved attending 6 weekly sessions on Zoom; each 2 hour session focused on different themes (e.g. communication, activities).

Reflections on the co-production process

Key ingredients of co-production included ensuring clarity on roles, positive communication and understanding of the family carers' situation and utilising the varied skills family carers can bring to research and practise.

Keywords: family systems, co-production, parent carers, lived experience, patient and public involvement

Background and rationale for Positive Family Connections

Family carers of children with a learning disability, or who are autistic, or have both conditions, are at greater risk of poor mental health (Rydzewska et al., 2021; Schnabel et al., 2020). Families are often under additional pressures due to isolation and difficulties accessing appropriate and timely support (Stanford et al., 2020).

Positive Family Connections was developed for families with a child aged between 8-13 years old. The rationale was that these family carers were more likely to have come through the potentially challenging early years but not yet entered the period of transition to adult services. It is, however, acknowledged that this period can still be tumultuous for some (e.g. transition to secondary school and onset of puberty). Positive Family Connections draws on three building blocks detailed below:

1. Positive orientation to disability

While not denying the additional challenges family carers can face, many report positives in family life, including valuing what is important, and improved and closer family relationships (Hastings, 2016; Jess et al., 2017). There are indications of a gradual shift in the research literature away from the predominantly negative narrative around disability and families (Griffith & Hastings, 2014; Hastings, 2016). The first aim therefore was to build on this positive approach.

2. Family systems approach

Second, a family systems approach acknowledges that the family is a system and each sub-system (such as parent-child, sibling relationship, parental couple) affects other sub-systems and individuals within the family (Cox & Paley, 1997; Wampler & Patterson, 2020). By enhancing the different relationships within the family the whole family benefit and the family can become a stronger unit (Walsh, 2003; Walsh, 2016). A related concept is that of family based 'social capital' where positive relationships, with shared norms and sense of belonging, lead to greater wellbeing (Furstenberg & Kaplan, 2007). This has been shown to be associated with positive outcomes for adults with learning disabilities (Tournier et al., 2021). However, there are few family-systems-focused interventions or programmes that have been developed for families with a child with a learning disability, who is autistic, or both (Glidden et al., 2021).

3. Co-production

The project's third building block was co-producing the programme with family carers, thereby utilising lived experience to ensure the programme was tailored to families' needs. Co-production is an approach in which researchers, practitioners and the public work together (NIHR, 2021) to ensure that research focuses on meaningful outcomes.

Of particular relevance for this cohort, working co-productively helps to break down the "them-and-us" positioning of family carers in relation to professionals that often causes them considerable stress (Griffith & Hastings, 2014). Co-production offers family carers valued roles which can help to break down others' negative attitudes towards them (Gore et al., 2022) and provide meaningful, paid work.

Furthermore, establishing groups with other families in a similar situation may not only reduce isolation but also offer a chance to share beneficial strategies and perspectives that can support wellbeing, thereby acknowledging the reciprocal nature of helping others along with being helped *by* others (cf. Gore et al., 2022).

The aim of the current paper is to describe the development process for Positive Family Connections and to reflect on the co-production process.

Development process

The programme, Positive Family Connections, was co-created with family carers and researchers and this was further supported by the first author being both a researcher and family carer. The programme was also designed to be delivered solely by trained family carers.

The Development Group

The Development Group comprised five family carers (two fathers, three mothers) of children with a learning disability or who are autistic and aged between 4-16 years old. Family carers were recruited via already established connections through research and parent carer networks. They were approached to reflect a diversity of experiences including their geographical location (Northern Ireland, the South West of England, North of England and London), ethnicity and family situation, as well as the child's diagnosis and age. The family carers also brought considerable additional skills; including prior experience of facilitating groups, competence in working virtually, and some knowledge of research processes. Family carer facilitators were employed for this project by the University and paid an hourly rate equivalent to a post-doctoral researcher.

The research team also included two researchers and a PhD student, all with experience in family research.

The Development Group met virtually four times over 9 months from March 2021. The initial meeting involved introducing the underlying themes of the programme and an outline of the proposed development process. Early on it was agreed that the whole programme would be delivered virtually; this was partly due to the potential for further COVID-19 pandemic-related lockdowns as well as increased accessibility for family carers who may struggle to attend face-to-face interventions due to difficulties with travel, childcare, or parent health problems (Lunsky et al., 2021).

At the second meeting the content of the programme, including the design and delivery of each session, was discussed. A draft proposal was tentatively shared (by researchers) to aid discussion. Considerable changes were made to the initial proposal by the family carers where, it was felt that each session would have a broader theme and family carers in the groups could apply the strategies and theories to their own family in a way that made sense to them. The Development Group also wished to provide practical take-home messages for family carers to apply to their lives, which became integral to the programme.

Discussions on ensuring inclusion for all types of families (i.e. by birth, affinity, or choice) led to the group decision that 'family' should be self-defined by participants in the programme to minimise any risk that participants might feel marginalised.

Other discussions centred around the positive approach of the programme and how to avoid a 'toxic positivity' (i.e. the avoidance, suppression, or rejection of negative experiences). Whilst all the family carers welcomed challenging the predominantly negative narrative around disability, they wanted to ensure the programme acknowledged the entirety of family carers' experiences, both positive and negative. Strategies were therefore included in the programme about ways to manage some of the stressors families may experience (e.g., how to balance everyday demands and making time for yourself).

Reflecting the discussions above, the name 'Positive Family Connections' was agreed for the programme.

Smaller working groups met in between the second and third group meetings to work on sections of the programme in greater detail.

The third group meeting involved bringing the sessions together and preparing for the next stages of the project.

The logic model for the programme, as agreed by the development group, is provided in Figure 1.

Overview of the Positive Family Connections Programme

The draft programme comprised 6 x 2-hour sessions. Each session involved a check in and check out and followed a similar structure. The overview of the session content is shown in Table 1.

A Facilitator Manual was developed with family carers and later incorporated further feedback from the family carers attending the pilot groups (see below).

Initial piloting of Positive Family Connections

The family carer members of the Development Group delivered two pilot groups as facilitators (in facilitator pairs, supported by the lead author).

Additional family carers were recruited to take part in the pilot groups via the parent carer networks of the facilitators and research team. The two groups were delivered consecutively, which allowed for amendments to be made to the programme following feedback from the first group.

Seven family carers attended each pilot group. All were mothers and their children had a learning disability, were autistic, or both and were aged between 5-16 years. All programme sessions were delivered and of those who started the group, 100% attended at least four of the six sessions. A further five family carers had initially expressed interest in attending the pilot groups but did not take part (due to clashing concurrent activities or their child's hospitalisation for surgery).

After each programme session, a researcher joined the group of family carers (once the facilitators had left) to seek immediate feedback on the programme (i.e. what worked well, what changes needed to be made, and any additional comments on the programme).

Concurrently, the two facilitators joined a breakout room together to complete a checklist after each session to indicate what components had been delivered (i.e. fully, partially, or not delivered) and their immediate reflections on the material delivered, including the flow of the sessions, topics, materials, and resources, and any further suggestions.

Family carers were not paid to participate in the Positive Family Connections sessions themselves. However, they did receive a voucher as a thank you for their time providing feedback following each group session. Facilitators were paid their hourly rate for preparation, delivery, and providing feedback as well as attending ongoing supervision.

During the pilot groups, regular and ad-hoc supervision was offered with the first author to provide a confidential space for facilitators to discuss any difficulties and celebrate successes. Topics discussed included managing family carer distress and group dynamics as well as practical issues such as supporting latecomers to the group.

Further changes were made to the programme in light of the comments from family carers and facilitators (e.g., a clearer overview at the start of the programme and using breakout rooms more often).

Where there were discrepancies in responses (e.g. one group suggested the need for more slides and the other, fewer) discussions were held with the Development Group for a final decision.

A final development group meeting took place to discuss feedback following the piloting and to prepare the materials for the next phase of the study.

Experiences, Reflections and Implications

The NIHR (2021) outlines 5 key features of co-production that we have used to reflect on the development process for Positive Family Connections:

1. Sharing of power – the research is jointly owned and people work together to achieve a joint understanding
2. Including all perspectives and skills – make sure the research team includes all those who can make a contribution
3. Respecting and valuing the knowledge of all those working together on the research – everyone is of equal importance
4. Reciprocity – everybody benefits from working together
5. Building and maintaining relationships – an emphasis on relationships is key to sharing power (NIHR, 2021).

To produce these reflections, the family carer members of the author team were asked to write their reflections about the process and share these with the lead author. The lead author then selected material to quote directly – to reflect the range of views expressed and to include each family carer author's perspective. The first draft of this section of the paper was shared with the family carer authors for their comments and approval.

1. Sharing of power

Decisions were generally made as a group including meaningful changes to the programme in response to family carer feedback throughout the process. At times, where there were differences of opinion and a final decision still had to be made, it helped that the first author was a family carer as well as a researcher. Furthermore, offering an 'open-door' approach helped to solve any potential difficulties early on and assist in building a team.

'At no stage during the development process did it feel like the delivery content was being artificially crafted to support "research" findings to the detriment of the lived experience provided by the family carers. The two aspects worked in harmony.'
(Family carer [FC]1)

'The feeling of a power dynamic dissipated during the development of the programme as each family carer came with their own experiences and skills. Initially not having a background in either research or psychology I questioned how valuable my contributions were, but as the group progressed these insecurities went.' (FC2)

2. Including all perspectives and skills

Family carers are not 'just' family carers and are not a homogenous group. They bring different experiences, perspectives and challenges including skills from previous or current workplaces (e.g., facilitated other groups) as well as being involved in different lived experience projects.

'All the family carers who participated had a wealth of knowledge and a breadth of skills. Over time we learned about each other's strengths and could see who in the group might be best suited to solving certain types of problems.' (FC2)

'I was very aware of being the parent of a teenager who at the time attended mainstream education. I was past a lot of the hurdles and experiences shared by some of the others or didn't experience. Not at anytime was my experiences trivialised or compared, quite the opposite.' (FC3)

3. Respecting and valuing the knowledge of all those working together on the research

Lived experience was paramount to the meaningfulness of the project. In parallel, the family carers appreciated the skills and support providing by the research team, including respect for the research process and ethical approach.

'I felt confident to use my lived experience to provide narratives for the programme. This gave me a deep sense of connection to the programme, which was enhanced further when facilitating.' (FC2)

'Because we were all bringing our lived experiences it made it a level playing field for all.' (FC3)

'The fact that we had a good mix of representation from across the UK was useful to consider variations in legislation and support that is available in the different nations. This has enabled the research team to include regional differences when widening the study for future pilots rather than "reverse engineer" it.' (FC1)

Consideration was given to tensions and sensitivities that can arise when using lived experience. While openness can forge intimacy and connection in a peer group there may be times when a family carer did not want to share their experience in the group which needed to be respected. While family carers were encouraged to access their personal experiences in the development and delivery of the sessions, discussions also took place over respecting when a family carer did not want to share their experiences and other examples were provided for facilitators to use. For example, if a family carer was going through a particularly difficult time with regards to an issue it might be best not to share that in the programme. Encouraging family carers to look after their own wellbeing prior, during and after facilitation of a group was key.

4. Reciprocity

Reciprocity between the family carers and researchers went beyond financial recognition of contributions made and included increased confidence, self-efficacy and flexible work experience for family carers. Researchers gained access to a greater pool of experiences to inform the programme based on what might happen 'on the ground'.

'It was a privilege to participate in this work, and also to be paid a professional wage for the time. Family carers give many hours of unpaid work to the system in a bid to make the world a better and easier place for others coming after and it can feel like a very long internship.' (FC2)

'I was pleased to take part in the development and delivery of Positive Family Connections, it gives me the fulfilment to support other family carers to improve the quality of life of their family unit.' (FC4)

'My participation was motivated by the desire to understand more about latest thinking, research and lived experience that could help me in my family carer role, while also having the opportunity to help other family carers improve their relationships within their family networks.' (FC1)

5. Building and maintaining relationships

It takes time to get to know one another as a team and there can be additional constraints when this takes place virtually. Allowing more 'informal' time in meetings, such as over a lunch for the normal 'chat' that would occur in a face-to-face environment supports this development.

'I have built great relationships with other family carers; as we all have caring responsibilities we could relate to each other. Sharing information and getting emotional support was some of the benefits of being part of such an amazing project.' (FC4)

'I am used to being the 'supporter' it was great to be on the receiving end of the support.' (FC3)

Sharing Learning about Co-production

As a team, we wished to add a further principle to the key principles of co-production (NIHR); that is the commitment to disseminating learning about co-production. A short film of the family carers discussing experiences of being part of the process was produced and an article about co-production was shared on the Cerebra website. It was hoped this would encourage a greater number of people with lived experience to get involved and remove some of the 'mystery' about doing research. It also highlights the benefits of co-production to other family carers and researchers.

Key ingredients for co-production:

The team reflected informally, through supervision and meetings, on the key ingredients for co-production work with family carers. All contributing authors provided feedback on this list as a part of the writing process for the paper. We suggest that key ingredients for co-production may be:

1. Understanding the context for family carers (including other demands and having backup plans).
2. Clear expectations and time requirements of the role from the start.
3. Simplifying administrative processes to reduce the burden on family carers.
4. Supportive and flexible liaison and supervision between researchers and family carers, including adapting to their preferred means of communication (e.g. WhatsApp, streamlining information into one email).
5. Allowing time for personal and professional development including relationship building to feel part of a team.
6. Appropriate funding to represent the value of lived experience.
7. Family carers are not a homogenous group so there can be a diversity of views. While this can be a strength, at times when someone needs to make a final decision it helps using research staff with lived experience (and being open about their position).
8. It is important to identify the overall skills needed to facilitate a group in the current context; which involved not just delivery of material (i.e. training) but also skills to manage discussions, including some that can become challenging.

Our conclusions reflect many of the themes identified in other co-produced and co-delivered studies with family carers (Borek et al., 2018; Pozniak et al., 2022).

Conclusion

The development process for Positive Family Connections provides a further example of family carers and researchers co-producing a programme for family carers. The accumulated literature clearly demonstrates the value in practice and in research to co-produce work with family carers; and offers some suggestions about how to go about meaningful co-production. The Positive Family Connections programme is now ready for initial feasibility research.

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