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Commentary on “positive family connections: co-producing a virtual group programme for family carers of children with learning disabilities or who are autistic”

Suzy Mejía-Buenaño

Abstract

Purpose – *The purpose of this paper is to provide a commentary on Griffin et al.'s paper, “Positive family connections: Co-producing a virtual group programme for family carers of children with learning disabilities or who are autistic”.*

Design/methodology/approach – *This is a commentary on co-production, drawing on Griffin et al.'s paper and the values base of the field.*

Findings – *Co-production is a valuable approach which seeks to empower and include key people in research. As suggested by Griffin et al., disseminating learning about co-production is an important additional principle of co-production, which demonstrates a values-based commitment to co-production.*

Originality/value – *This commentary is aimed at professionals and researchers working in the field of learning disabilities who are keen to learn about and do co-production.*

Keywords *Learning disabilities, Co-production, Intellectual disability, Family support*

Paper type *Viewpoint*

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This paper described the development of a co-produced virtual group support programme called Positive Family Connections. The programme was aimed at family carers of children with a learning disability or who are autistic and who are also aged between 8 and 13 years. The programme drew on three approaches: co-production as a central element to the development of the programme, and the development of which was described in depth in the paper; a family systems approach which allowed for the consideration of the family as a system and the ways in which sub-systems within the family could affect other individuals and sub-systems within this family (Cox and Paley, 1997; Wampler and Patterson, 2020); and taking a positive approach to disability, which was in contrast to the predominantly negative approach which is taken with disability and families (Griffith and Hastings, 2014; Hastings, 2016). The paper then describes the process of developing the programme and concludes with reflections from the Development Group about the programme and the process of its development. This paper provides insight into the process of using co-production to develop programmes for families, and the reflections from the Development Group provide a rich demonstration of the value of undertaking a co-production approach when working with families. The authors also discuss the five key principles of co-production, as outlined by the National Institute for Health and Care

Research ([NIHR, 2021](#)) and propose the addition of a further sixth key principle. In this commentary, I will discuss the importance of co-production, co-production as a value which is aligned with the values of the field and the concept of the addition of a further key principle of the commitment to disseminating learning about co-production as a further key principle of co-production ([NIHR, 2021](#)). While Griffin *et al.*'s article focuses on co-production with family carers of children with learning disabilities or who are autistic, my commentary will focus on co-production more broadly and at times will focus more specifically on co-production with people with learning disabilities. Throughout this commentary, the discussion will focus primarily on co-production in research, as this is the scope through which Griffin *et al.*'s article has discussed co-production; however, some parallels will be drawn with the relevance of co-production in clinical practice, as this is also pertinent and relevant in practice settings.

Co-production and its value

At its core, co-production is about involving experts by experience (e.g. autistic people, people with learning disabilities, family carers of people with learning disabilities and/or those who are autistic, etc.) and professionals in the design of research ([Liabo *et al.*, 2018](#)). The aim of this approach is to ensure that research is focused on addressing questions which are pertinent to those who access services, improve the acceptability of interventions and focus on meaningful and valued outcomes ([Liabo *et al.*, 2018](#); [NIHR, 2021](#)). Historically, approaches to including people with learning disabilities in research were consultative in nature, and true co-production was rare. There has recently been an increase in the emphasis on co-production in research involving autistic people, people with learning disabilities and family carers ([Armstrong *et al.*, 2019](#), etc.).

Historically, research has shown that people with learning disabilities have been excluded from research ([Feldman *et al.*, 2014](#)). Co-production presents a way to ensure that people with learning disabilities, autistic people and family carers have equal access to being involved in research by virtue of involving people from the outset. In this way, it would be unlikely for research to be designed in a way which would be exclusionary for key people. For example, Griffin *et al.*'s paper includes family carers in the development of a programme for family carers. This has resulted in the development of a programme for family carers which has considered their unique needs and circumstances and has influenced the design of the programme to ensure that family carers are more able to attend (e.g. by making the programme virtual to address the challenges family carers may face if required to attend an in-person event). This approach demonstrates a commitment to improving the lives of key people, which is generally considered to be a value of the field. While the Positive Family Connections programme has been developed to be used in research in a future feasibility randomised controlled trial, this same process could be undertaken in clinical practice for the development of programmes for families.

With respect to people with learning disabilities, co-production has been seen as a method of inclusion that redistributes power to people with learning disabilities, supporting them to be active agents of change and giving them control ([Tardiff-Willaims *et al.*, 2009](#)). Clearly, co-production has value not only when involving family carers but also people with learning disabilities or autistic people. These are some examples of the meaningfulness of co-production and are by no means intended to cover the range of ways in which co-production brings value to research and clinical practice.

The value of co-production

The commitment to co-production is a value akin to those of earlier movements, which aimed to include and value people with learning disabilities (e.g. normalisation and social role valorisation). The aims of movements such as these were to create and support valued

social roles for people that were at risk of being devalued and to support people to live normal lives (i.e. support people to live their lives normally, not conforming to a preconceived standard “normal”; [Culham and Nind, 2003](#); [Wolfensberger, 1983](#)). Along the same lines, co-production seeks to involve people with learning disabilities, autistic people and their family carers in the design of research, valuing their contribution and allowing experts with experience to not only guide research but also have a staple role in an area that has historically not held the same space for key people. Some ways in which Griffin *et al.*'s article demonstrate values-based actions for co-production include the following: a family carer wrote the article; the programme itself is only delivered by family carers; the non-family carer members of the research team and Development Group were open to change stemming from family carers' input, indicating a reciprocal nature of the approach; and there were excellent and thoughtful reflections made from family carers in the Development Group, which showed that they felt respected and listened to in their roles.

A particularly interesting contribution to Griffin *et al.*'s work is the proposal of an additional key principle of co-production. The National Institute for Health and Care Research (2021) describes five key principles of co-production: sharing power, including all perspectives and skills, respecting and valuing the knowledge of all those working together on the research, reciprocity, building and maintaining relationships. Griffin *et al.* propose the addition of a sixth principle of co-production, which is the commitment to disseminating learning about co-production. It is my opinion that there is merit in this addition as a key principle of co-production, as it represents a commitment to furthering knowledge about co-production and supports the provision of further examples of how to go about doing co-production – this is also a values-based action for co-production. There are some examples of this in the literature ([Armstrong *et al.*, 2019](#); [Roberts *et al.*, 2013](#)); however, further models for how to co-produce programmes or research allow for different approaches to be described and details to be provided, which others can then learn from. For example, this paper discusses the payment of family carers. One way in which this information is helpful is that it allows researchers to have a model from which to cost the time of those being sought to be included in co-production. In the development of the Positive Family Connections programme, family carers were paid an hourly rate equivalent to that of a post-doctoral researcher. This transparency with the details related to the process of co-production helps to pull back the curtain on how to carry out co-produced work (e.g. costing people's time when applying for grants, compensating people fairly for their time, etc.). Additional considerations which warrant consideration in future co-production work are logistical barriers such as payments potentially impacting benefit payments and if the co-production work is short-term rather than ongoing, a potential overall negative impact on an individual's financial circumstances as a result. Given that co-production has not historically been the norm in learning disability or autism research, it is feasible that it may be viewed as a challenge to implement; however, publications like this provide helpful examples of co-production in action which can be used by others intending to undertake coproduction.

Concluding thoughts

It is my opinion that Griffin *et al.*'s article provides an excellent example of iterative work, which has embraced changes to the Positive Family Connections programme resulting from the role of family carers in the Development Group. The paper proposes an additional key principle of co-production in the form of a commitment to sharing and learning about co-production. This is aligned with the value of co-production as it provides an example of a method of carrying out co-production work as well as describing the experiences of those involved and reflecting a values-based approach to disseminating lessons learned about co-production. While the rationale for co-production is clear, it is not inconceivable for there to be a perception that there may be barriers to carrying out co-produced work, given that this has not the norm in learning disability or autism research. Therefore, seeing further

examples of the actions which show how to *do* co-production is helpful to researchers and clinicians, particularly when there is transparency in these examples, as there has been in Griffin *et al.*'s article. It is my hope that we continue to learn more about ways to do co-production as a field and that we continue to involve people with learning disabilities, autistic people and their family carers in this way. It is clearly at the heart of the values base which guides our field.

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