



Thursday, 3rd of March 2022
(1:30pm – 3pm)

Carers Space Notts: Session 2
Carers' Experiences of Co-Production
Summary

For additional information and opportunities to get involved in co-production projects, please visit: <https://nottinghamshirecarers.co.uk/carersspacenotts>

There were 22 attendees at this session (11 carers, 7 professionals and 4 professionals who were also carers).

Welcome

- Helen Yates gave an introduction to Carers Space Notts for new members. A summary of the group's aims and objectives can be viewed in the "about us" document on the Carers Space Notts website.
- Presentation slides and notes including questions and answers from the previous session on the new approach to carer assessments are available on our website.
- Nottinghamshire Adult Social Care is also producing a video to explain what a "person-centred approach" to assessment means and how it works. This will be available on our website shortly.

Introduction to Co-Production

- Person Centred Planning Manager Sarah Craggs (Nottinghamshire Adult Social Care) gave a presentation on what co-production is and what it can look like. Slides summarising this are available on our website.

Alison Fisk - Parent Carer and member of the Co-production Steering Group "Our Voice"

- Over many years Alison has been involved in various groups both within education and social services as a carer and advocate for her son.
- She has been involved in groups where parent carers have had some influence, such as the East Midlands Special Educational Needs Regional Partnership.
- In other groups it was engagement rather than co-production.

- **Carers Implementation Group:**
 - Good level of engagement with carers.
 - A lot of information was provided for comment and queries.
 - Carers were also part of the tendering process and interviews for appointing an organisation for carers.
 - There were instances where issues were raised or topics suggested where the chair decided they would not be discussed.
 - Carers were not seen as equal partners, only having influence as far as allowed by those in charge of services.

- **Learning Disability and Autism Partnership Board.**
 - Carers could only put in written questions and receive written answers 2 months later.
 - A lot of information was given, but often little follow-up.
 - Mutual lack of trust between council officers and carers so nothing really changed.
 - It felt tokenistic.

- Alison has had good experiences with Social Services in the past.
- Since then, she has had several difficult encounters with some social care staff, resulting in a number of official complaints.
- Alison felt that when money needed to be saved, the idea of following the letter and spirit of The Care Act went out the window. The wellbeing of Alison's son ceased to be central to decisions.
- Alison chose to get more involved in the carers' groups, as she knew many others would have had similar experiences.

Improvement

- The change came with the new Director of Social Services.
- Alison read up on co-production and saw that it could be a radical way of working. It was being championed from the top by Director Melanie Brooks.
- Already knowing and trusting Sarah Craggs, and after building trust with Melanie, Alison felt that she could go forward and embrace co-production.
- Alison had never before felt the sense of empowerment that being an equal gave her. Her experience and expertise in the area were finally acknowledged.
- Now Alison is able to help in shaping services so that others can be heard and changes made to make things better.

Speakers

Catherine Shatwell – Parent Carer for son, Manager of Reach Learning Disability’s Carers Matter Project

Disability Related Expenditure (DRE)

Situation

- From April 2019 Nottinghamshire County Council’s policy was that higher rate disability benefits could be taken into account, and the minimum income guarantee levels applied when calculating what level of contribution each individual person needed to make to their care support.
- A £20 weekly allowance was given to everyone towards their disability related expenses, but inevitably some people’s costs exceeded this amount by a lot.
- This effectively meant that the amount of money from your benefits which you could keep was reducing.

Problem

- Catherine had a need to request an increased DRE for her son as he has an assistance dog which carries a considerable cost over the £20 weekly allowance.
- The request process was challenging as there was no clear guidance either for the public or council staff.
- In addition, working for Reach, there were other carers with DRE related questions that needed clarification. So, Catherine had a lot of communication with the council on the subject.
- Clearly carers and the council weren’t agreeing on what was classed as DRE.

Co-production

- Catherine, along with some other carers had the opportunity to meet a team manager from Adult Care Financial Services (ACFS). The subject also seemed challenging for them due to the lack of written guidance.
- When co-production was suggested and embraced by the council it was seen as a way of potentially solving the DRE issues.
- Due to Catherine’s involvement, she was invited to join a task and finish group.
- The group consisted of a service user, another carer, a team manager from ACFS and a Person-Centred Planning Training & Development Manager
- The team provided a broad wealth of experience and worked well together even though at times it did involve challenging negotiations.
- The group came together during COVID restrictions, so it met on Teams. This proved to be convenient and productive

- All members inputted into a terms of reference document, helping to keep focus.
- Correspondence was shared by email
- Whilst the group members had other responsibilities, they didn't find it too onerous.
- On occasions there was pressure to meet deadlines, but without deadlines the group may well still be working on the guidance now.

Outcome

- The group was successful
- All members had the opportunity to use their experience to input into the guidance.
- It was empowering to be able to speak directly to senior leadership and ACFS and be heard by them.
- The leadership team recognised the financial implications of implementing the guidance, but also recognised the need for a fair process.
- ACFS were very supportive, worked hard drafting the guidance and respected our input.
- The team manager was as determined as the rest of the group to make a difference within the guidance. It really felt like a team effort.
- Whilst it took well over a year to finalise the guidance and obtain approval, the euphoria all group members felt at succeeding far outweighed the length of the journey.
- Lessons were learned by all members which will undoubtedly help in future co-production projects.
- The guidance will be revisited annually to update costings and inevitably make improvements.
- Catherine can strongly recommend that carers bring their experience to co-production and hopefully make a real difference to people's lives.

Adrian Hartley – Parent Carer for son with complex needs living in supported living

Updating Nottinghamshire County Council's Complaints Policy

Situation

- The complaints policy needed to be refreshed to rectify issues known by the council
- Because Adrian had experienced a few issues requiring him to make complaints as a carer, he was identified by the complaints team and invited to get involved in a task and finish group.

Co-Production

- The group was an equal mix: 2 carers with lived experience of using the service, a Group Manager for Living Well and a Complaints Team Manager.
- We also had a Quality & Standards Manager who chaired a forum for parents and carers to engage with commissioning projects.
- The meetings were co-chaired by the Group Manager and a person with lived experience.
- They went through the principles of co-production and all group members agreed a terms of reference document
- It was agreed that all complaints needed to deal with the issues raised, be respectful and be easier for people to receive and understand, taking into account their particular needs.

- The group had 3 tasks:
 - 1) To look at the complaints guidance for staff and to see if it needed any changes.
 - 2) To design the content for the staff training program to help improve consistency in practice
 - 3) To consider how best to check the quality of the complaint outcome letters sent out to people.

- It took a number of meetings with the policy circulated for comment in-between to speed up the discussions. It probably took 6 months overall to go through the process.
- People who use the service and their carers were able to highlight how services were not working for them, allowing an improved policy to be shaped.
- A lot of links to information and contact details to support services were included where appropriate.
- An eLearning module was developed for staff to explain the new complaints policy.
- The group members all took the training course in order to review and comment.
- It was planned to make the module mandatory throughout the entire council.

Outcome

- All group members felt that the group worked well together. It was very effective and collaborative. Everyone came to the table with different experiences and viewpoints which was helpful.
- Working in a small group enabled everyone to contribute and ensured everyone's voice was heard.

- We shared learning with the co-production steering group, looking at what had gone well. The group tried to identify anything that they had struggled to resolve, but fortunately it had gone smoothly.
- The group felt that the updated policy was greatly improved and more appropriate.
- The group also produced an accessible (easy-read) version of the policy to make sure everyone had the opportunity to understand what was being concluded.
- All sides came to the project with open minds, listening and acting in the common good, resulting in a much-improved policy.
- One of the experts by experience described the group as a success story

Marion Wardill – Carer for husband with MS

The Co-Production Strategy

- Marion came into the co-production steering group (Our Voice) via the Experts by Experience.
- The mantra of the group is “better together”
- Working with council officers, creating an equal partnership, developing relationships and having conversations where carers are listened to and can listen to professional colleagues.
- This is driving the group with the creation of a strategy and a way that co-production can be carried forward.
- The group can tackle issues such as communication and working on the possible barriers to people becoming involved.
- This is an active, growing group which needs extra people to share their input at the time of co-designing a policy.
- The group wants to be there at the beginning, middle and end of policies that affect service users and carers.
- Marion came into this role because she experienced having things foisted upon her and wondered why they didn’t ask for carer input.
- She had the opportunity to say what she thought at a meeting several years ago when the council were asking what carers thought about home care.
- Home care has improved as a result of the involvement of the Experts by Experience group
- The steering group is being asked to contribute in lots of other situations but need more carers to be involved.
- Carers are supported and inspired by some very enthusiastic people in the senior leadership who are committed to co-production.
- Any carer is welcome to join the Our Voice group and contribute however they can

The Joint Carers Strategy for Nottingham and Nottinghamshire

Situation

- Pam responded to an email from TuVida (Nottinghamshire Carers Hub).
- Like Marion, she felt that things were often done TO carers without carer input. For example, a consultation would be presented, but it's a choice between option A or B that have already been decided.
- Maybe if carers are involved in designing the Carers Strategy from the ground-up, they could make some changes.

Co-Production

- Pam initially didn't hold out much hope, but was pleasantly surprised when it began.
- She initially felt "foggy". In the first meeting she wasn't sure what was going on. It became clearer over time.
- Everybody has been so passionate about working with each other as equals, it's been really enjoyable.

- The group has been developing a 5-year strategy alongside Nottinghamshire County Council, Nottingham City Council and the Clinical Commissioning Group.
- All working together for carers. Looking at what carers need in a holistic way.
- Pam is really excited by the strategy which is due to go out to wider consultation shortly.
- Right from the beginning the carers were seen as equals which was really empowering and their experiences have been really valued.

- The process began with a series of group meetings facilitated by Nottinghamshire Carers Association, talking about key components for the strategy
- Several of the carers began to sit on the main strategy board, speaking directly with commissioners.
- Pam was surprised by how enthusiastic the commissioners and senior leadership were.
- The officers even changed their own opinions after hearing experiences from the carers.
- Sometimes the carers had to stay firm on things, and were listened to rather than being dismissed.

Outcome

- The group is still very heavily involved in designing the consultation process.
- When the development of services to be commissioned begins, the group will continue.
- Currently at the stage with the strategy where more carers are needed to be involved in coproducing the next steps.
- Carers may feel that they may not have much to offer, but actually those stories are really powerful because they are lived experiences.
- Pam really recommends people get involved, as little or as much as they want.

Questions and Answers

- **Trevor**
 - Stories are really encouraging and made me feel that there was some forward movement.
 - I myself have experienced some frustration in co-producing at all levels, particularly at board level.
 - Developed a 4-point plan for working co-productively
 - Make sure there are no hidden agendas
 - Feedback from professionals is essential whether or not they decide to use carers' input
 - Active listening needs to be used by all parties
 - Lived experience means you have worked with the system. It enables you to ask in-depth questions when listening to other people's points of view.
- **Pam**
 - Not sure Trevor has experienced true co-production, but the old-style engagement instead which we all put up with.
 - What we have experienced recently is true co-production. We're right in at the beginning.
 - We're not invited just to give our views. We're not only getting feedback on what's happening, we're actually there at every meeting.
 - You see who is given tasks, hear the feedback on what they've been given tasks on, what's happened. You are very much part of that group.
 - The whole ethos has changed from the top down and now carers are seen as equals with valuable contributions.

Helen Yates - How to get involved in Co-production

- May sound from some of the stories that getting involved with co-production is like having a part-time job. It can be depending on the project, but we're interested to find out about how you can be involved in different ways.
- It doesn't have to all be lengthy Zoom calls. It can be via email exchange or shorter telephone calls for example.
- Please don't be put off thinking it's all lengthy meetings and too much commitment. There are lots of things going on in different projects that you would be able to tap into in different ways, taking up different amounts of your time.
- **There are three projects available at the moment. (More details: <https://nottinghamshirecarers.co.uk/opportunities-for-carers>)**
- Professionals who wish to recruit carers for future co-production projects will have access to a form to fill in to explain to carers what that project looks like, how their involvement will work, what you're hoping to achieve. This can that be shared through Carers Space.

Breakout Groups

Barriers/issues to consider

Group 1

- Attracting working age carers and enabling them to take part in this space
- Helping people to find out more. What information do people need to feel that they're able to take part?
- Artificial barriers, avoiding a "them and us" situation.

Group 2

- Finding ways to help people know about how and what they can get involved in

Group 3

- Need for training on co-production to be sent out to a lot of staff to make sure they are fully aware of it and spreading the message. Inviting service users to be a part of that training.
- Carer diversity. Making sure everybody is involved and represented.
- For commissioners to be realistic in what they are expressing to carers. Carers may have unreasonable expectations of co-production.

Group 4

- Need to be mindful of language used. Reduce the amount of jargon.
- Making sure Carers Space Notts is promoted far and wide to reach as many carers as possible.
- Need to demystify co-production. Keep working to explain the purpose of co-production
- Explain and promote successes. What change has been achieved through co-production already

Group 5

- Work & time.
- Demographics of who is involved, how to get the word out.
- Getting young carers involved
- Technology – occasionally meeting face to face now that COVID restrictions are lifting.
- Fear, anxiety, people not believing they're going to be heard.

Contact Information

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