

Co-producing service improvements for children and young people with complex needs



What was the focus of the co-production work?

Cambridgeshire and Peterborough Clinical Commissioning Group (CCG) identified that families with children and young people (CYP) with complex needs were underrepresented in parent and carer forums. It also recognised that the commissioning boards lacked a strategic overview of the requirements of this group. Due to their complex medical needs, these groups are at higher risk of poor functional status, quality of life and health outcomes. This project aimed to work with people with lived experience and their family and carers, to improve the experiences of integrated community healthcare services for those aged 0-25. A secondary aim was to use the learning from this work to produce a toolkit to bring together overarching principles of co-production with CYP.

"They're a group that the system, in general, hears little from."
(SEND Health Lead, Interview)

Recruitment and engaging with people with lived experience

The project group conducted a stakeholder analysis to identify those who would be appropriate to engage with. This included charity organisations like Little Miracles, Liam Fairhurst Foundation and East Anglia Children's Hospice. In addition, the group built relationships with individual families at Cambridge University Hospital Trust who are already working in other groups to co-produce change. To aid recruitment and engagement, the project lead:

- o ensured flexibility in timings and preferred approach for charities
- o recognised the importance of relationship-building
- o provided clarity on the intentions of the project and its benefits for CYP.

Understanding what matters

Co-production was very important to the staff, and they often took moments to reflect on the balance of input from those with lived experience. Initial stakeholder meetings indicated that the focus of the work should be around experiences of transition to school and/or to adult services. However, it was quickly recognised they needed to engage with a wider group of people before focusing on a particular aspect of care. A broader easy-read survey was then developed to understand children and young people's experiences and thoughts on their healthcare. Parents and carers were also invited to complete the survey.

The survey asked for the 'top three' issues or concerns that participants have regarding their healthcare or support. It also asked whether they wanted to share more healthcare details and/or join the co-production group. It was hosted online and was also available as a PDF, to print and return on request. The survey collected 62 responses: 16 from children and young people and 46 from parents/carers.

The team also used slide, an online Q&A and polling platform, to engage with 24 parent representatives and health professionals. This explored gaps or challenges in collecting feedback and identified potential solutions to some of the difficulties highlighted.



Building foundations for co-production

- o It is hoped a co-production approach will be used for all service improvements in the future. Some parent/carers forum members suggested the team create an engagement calendar to plan how they will engage people with lived and learned experience throughout the year.
- o A key finding from their engagement work is the difference between staff and people with lived experience on the preferred method for engagement. Those with lived and learned experience reported feeling more comfortable talking in focus groups. However, this was the least used method by healthcare professionals.
- o Members of the group with lived experience reported the project had helped them see where changes were starting to be made. The team plans to continue measuring the impacts of the co-production work on children and young people and their parents/carers.

Key challenges



Understanding co-production. Understanding the principles of co-production can be challenging for staff that are unfamiliar with this approach. The team noted that it would require 'workforce development' to help staff understand how co-production can be achieved.



Recruiting people with lived experience. Some families are understandably time-poor and only access support in specific groups or situations. This made it more difficult to recruit members to the co-production group. Greater social isolation due to Covid-19 was felt to have contributed to the recruitment difficulties.



Increasing the diversity of voices heard. The group engaged with a wide range of people, but recognised that they still missed certain groups. Recruitment is ongoing, and staff are continuing to seek out and invite people with lived and learned experience to join the co-production team.



Barriers to engagement. The group identified a need for future projects to include interpreters, those from the travelling community and people with limited access to the internet.

Understand preferred methods of engagement.



Key learnings



Length of time. The team learned it is important to be realistic about the length of time it can take to use a co-production approach. Identifying who to involve, how to engage them and ensuring there are sufficient resources was more time consuming than expected.



Providing feedback to people with lived experience. The team wanted to 'close the feedback loop' to ensure that the voices of the people with lived and learned experience have truly been heard. They plan to share a report on their work's impact with those who contributed.



The importance of active listening. Rather than making notes or paraphrasing, the team recognised the value of actively listening, such as paying attention to the conversation and observing non-verbal communication. It was felt active listening allows for a richer understanding of the views and experiences shared.



Linking with other work. This project has been a driving force for greater linkage between different projects being conducted within the system. There are system-wide overarching principles of co-production that this work will feed into.



"This initiative has helped me to link in with other pockets of work that are going on in our system, and really be a driving force to link them up."

(Clinical lead for children with complex needs, Interview)

Next steps

- To conduct focus groups and other engagement approaches to understand what is important to children/young people and their parents/carers and then work with them to develop service improvements.
- To develop a toolkit to support staff in understanding the key principles of co-production with children and young people. This will be based on the learnings gained from this project and other co-production work being conducted across the system.

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