

Transforming Children's Continuing Care

INTRODUCTION

It is widely acknowledged that the demand for complex care is growing year on year. This is due to advancements in medical technology ensuring longer lives for children with the most complex physical needs and changes to the framework for Continuing Care to recognise the health needs of children with behaviour that challenge.

Improving the experiences, outcomes for families whilst ensuring value for money across the system is a key objective therefore engagement and co-production will be fundamental to shaping how those aspirations will be delivered.



PROJECT DESCRIPTION

To design an innovative user engagement plan for children and their families with complex needs, recognising that many parents and children describe feeling 'engagement weary' because their well-documented views and experiences have not led to meaningful improvement.



THE JOURNEY

Halfway through the course my role changed significantly. Starting to lead the transformation of children's continuing care created the opportunity to think creatively how to ensure a stronger focus of engagement, collaboration and co-production.

The study days were invaluable in providing a space to think, be curious, test ideas through action learning sets and challenge how to deliver meaningful innovative engagement.



ACTIONS TO TAKE FORWARD

- 1. Understand the research gathered to date**
Preventing families being asked to become involved in a project where they have already shared their views and experiences. Be realistic regarding intended benefits.
- 2. Seek the views of existing users and their families**
All families undergoing a continuing care assessment are asked to complete a short survey using a variety of formats to include; in person during a review visit, electronic (anonymous if required), social media groups, transformation/ co-production group and attendance at existing user groups, for example Hampshire Parent Carer Network. Draft user survey and consult with current user contacts to check if user friendly and fit for purpose.
- 3. Retrospective views of families**
Who either have Continuing Care provision and where eligibility has not been agreed.
- 4. Information from the surveys and user co-production groups to be part of a quality improvement cycle**
Aligned to Continuing Care service redesign plans, test local intelligence with established national narratives based on extensive engagement.
- 5. Parent and young person representative to attend the Complex Care Transformation board.**
Ensure clarity how the representatives will cascade information both from and into the board.



KEY LEARNINGS/REFLECTIONS

Starting a new role at a senior level across HIOW meant that it was at times challenging to maintain focus on the engagement project. However constant change is a reality in health & social care.

The drive to champion complex children and their family's involvement in shaping and improving services should be constant and a priority. The leadership module supported clarity around proactive purpose and concentrating on areas of influence.

Cascading the learning whilst providing authentic inspirational leadership to motivate the team to deliver an engagement programme has been supported by the tools and expertise of the external experts.



Huge thank you to Sue, Paul and the external speakers for sharing their knowledge and expertise in such an accessible manner.

Thank you to the Children's continuing care team for committing to ensure that children and families voices will drive our transformation.

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