Embedding

Young People's

Participation in

Health Services

New Approaches

Book Review: Embedding Young People's Participation in Health Services: New Approaches edited by Louca-Mai Brady

In Embedding Young People's Participation in Health Services: New Approaches, Louca-Mai Brady brings together contributors to explore the potential for inclusive and diverse approaches to young people's participation in health services. This collection will be relevant reading for academics, professionals or involvement officers who would like to learn more about how to embed young people's participation in their work.

This review originally appeared on LSE Review of Books. If you would like to contribute to the series, please contact the managing editor of LSE Review of Books, Dr Rosemary Deller, at lsereviewofbooks@lse.ac.uk

Embedding Young People's Participation in Health Services: New Approaches. Louca-Mai Brady (ed.). Policy Press. 2020.

Public and patient involvement have been embedded in the United Kingdom in recent years. Research shows that participation benefits both patients and health services, and it is included within the UK's legislation. Yet there still exists a gap between thory and practice. This is especially visible in engagement with children and young people. Involvement has no age limit and in her recent edited collection, Louca-Mai Brady brings together contributors to explore the potential for inclusive and diverse approaches to young people's participation in health services. Brady is an expert in the involvement of young people, and this book builds on her PhD research.

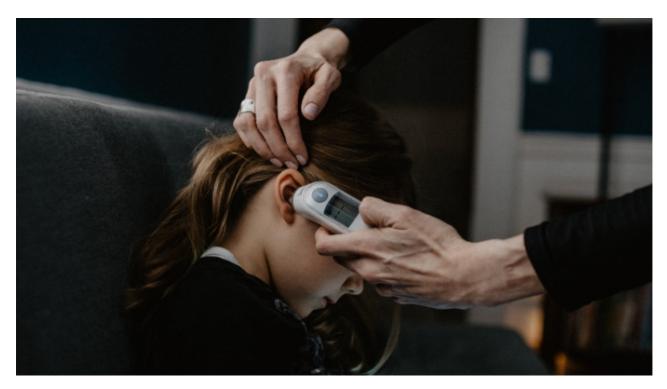
What makes this book stand out among the growing literature on young people's participation in health services is its diverse range of contributors. These include not only researchers and practitioners but, most importantly, young people themselves. The book provides an insight into what participation means to young people. Lizzy Horn, one of the young authors, explains why participation is important to her:

Knowing that I could be a part of preventing some of the struggles I had within services, for the next young people coming through them, was what motivated

me to get involved in participation. Not only did I want to see changes, but I myself could be part of that change. (1)

Reading this book during the COVID-19 pandemic is timely. Public and patient involvement was often lacking in the first months of the pandemic, as there was a need for a quick response. However, Brady points out in her postscript that 'the challenges of COVID-19 have highlighted the potential to do things differently, and develop more participatory and inclusive practice in collaboration with young people' (18). Thus, this book is not only an example of pre-COVID engagement with young people, but should also encourage a reader to reflect on how to utilise these lessons in future work during the pandemic.

The book is structured around four related sections: young people's participation in individual decision-making (Chapters One and Two); examples of involvement in national projects and programmes (Chapters Three to Five), collaborative research in NHS services (Chapters Six and Seven); and cases of young people-led participation (Chapters Eight and Nine). These are well-linked, and all themes are brought together in the concluding Chapter Ten, which proposes a new participation framework. Each chapter is worth an in-depth read. In this review, I look in detail at three chapters which perfectly exemplify the underlying message of embedding young people's participation in health services. I could not put the book down once I began reading them.



Some of the contributors share personal experiences which make reading this book both powerful and inspirational. In the second chapter, Zoe Picton-Howell draws on her research and lived experience as mum to Adam Bojelian, a poet and healthcare advocate who had a severe physical impairment, in order to discuss disabled young people's participation in end-of-life decisions. Her study is based on a survey and in-depth semi-structured interviews with paediatricians. She discusses guidance on young people's involvement and then explores how it is applied in practice. The findings show that some paediatricians were reluctant to recognise a young person's right and capability to take part in decision-making:

As Adam's life and death showed, and as senior paediatricians from around the UK in my research confirmed, fulfilling young people's rights to participate in decisions about their healthcare is not just a legal obligation, it is a matter of life and death (70).

Thus, Picton-Howell finishes with a recommendation to provide more teaching opportunities for healthcare professionals. This chapter highlights the importance of involving young people in healthcare. More information about Adam's life can be found here.

In the fifth chapter, Lindsay Starbuck, Kirsche Walker, Jack Welch, Emma Rigby and Ann Hagell discuss how to involve seldom-heard voices among young people. They use the experience of youth engagement projects run by the Association for Young People's Health, which is the UK independent voice for youth health. Each project engaged with one seldom-heard group, including young people affected by child sexual exploitation, young people living with HIV and young people who had weight issues. This chapter is full of quotes and case studies from young people that provide a lot of insight into the process. One of the participants of the Be Healthy project, which aimed to allow young people to discuss the health needs of youths affected by child sexual exploitation, described some of the challenges for seldom-heard groups:

One of the huge difficulties for young people getting and staying involved in projects like this is that we become known for our past experiences. I found it extremely hard to talk about my experiences and deal with the attention that it brought to me. (145)

The chapter concludes with practical pieces of advice on involving seldom-heard youth. The most important one is to check directly with young people what their needs are and then implement them. Building a lasting and trusting relationship can be a long process. Other tips include paying young people's costs in advance (as not everyone can wait to be reimbursed) and working in partnership with local organisations who could assist in reaching diverse voices. Furthermore, the authors recommend using distancing techniques such as fictional characters for discussion. Also, creative methods such as storytelling or film can facilitate the group in raising issues while protecting the identity of participants.

In the final chapter, Brady builds on both her previous research and the work in earlier chapters to propose a practical new framework for embedding young people's participation. She argues that successful participation must be youth-centred, and so places young people in the middle of her model. Youth participation is enclosed by what she calls 'scope' – 'a series of interconnected dimensions [...] all of which play a part in determining both what young people will participate in and how they will participate' (261). These include the structure of participation, its process, frequency, where it takes place, inclusion and diversity of youth voices, power and control and learning from participation. Key questions to consider are suggested with each dimension. This model will be especially helpful for anyone who would like to embed young people's participation in their services. The model's design does not suggest one way to engagement but encourages users to reflect on how to involve young people 'in ways that are meaningful, effective and inclusive' (262).

In over 250 pages, contributors cover a wide range of examples of how to involve young people in health services. Still, the book's insights are transferable to other areas which aim to involve young people: for example, social work, education or youth democracy. Thus, this book is relevant reading for academics, professionals or involvement officers who would like to learn more about how to embed young people's participation in their work.

Note: This review gives the views of the author, and not the position of the LSE Review of Books blog, or of the London School of Economics.

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