



Improving maternity care and experience for parents with learning disabilities

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Summary

This Individual Development Award funded me to explore the acceptability and perceived impact of Together Project resources within one NHS Trust. Health Education England provided additional funding (£99,468) to extend the study, and I recruited a further three NHS Trusts.

Phase 2 of the Together Project was successful in identifying the barriers and facilitators to implementing Together Project resources to support person-centred maternity care for parents with learning disabilities. It highlighted the value of working with both experts by experience (people with learning disabilities) and experts by profession (e.g. midwives and learning disability nurses) in developing and evaluating resources to support the delivery of good care for people with learning disabilities. It has also demonstrated the value of a multi-disciplinary advisory team (including Elfrida Society Parent's Project) which helped to further modify the resources, ensuring the refined innovative resources are relevant and meaningful to the population they intend to benefit. Overall, this study supports the acceptability and impact of Together Project resources in ensuring the voices

of parents with learning disabilities are invited and heard during their journey to baby and beyond. Midwives reported that the Together Project resources had a positive impact on their skills and confidence in recognising and supporting parents with learning disabilities, enabling them to reflect on how they deliver care to parents with learning disabilities and how they could do things differently in the future.

Public and Community Involvement

Public and community involvement were an integral part of the project from start to finish as outlined below.

An expert by experience (Scott) was a paid member of the project team and meaningfully shaped the development, delivery, and dissemination of the project, including:

- Co-delivering a presentation of the Together Project findings at the MidSoc conference to 450 midwives in May 2022;
- Co-delivering a presentation of the Together Project findings as part of a Health Education England 'Learning Lunch' in October 2022;
- Co-delivering a presentation of the Together Project findings and facilitating discussion of the Together Project resources with student



midwives at the University of Surrey in October 2022.

The Elfrida Society Peer Support Group for parents with learning disabilities advised the Together Project, as experts by experience. I visited the Elfrida Society in Islington six times to discuss the Together Project. At each meeting, I fed back on the current status of the project and sought feedback and contribution from parents. Amazon or Tesco vouchers were offered as a thank you for contribution at each engagement. Changes to the project as a result of these meetings include:

- A short film of parents with learning disabilities advising midwives on why the study is important and how they can help;
- Creation of an audio/visual participant information sheet for parents with learning disabilities;
- Improvements to the Maternity Passport (e.g. more images, colour and personalisation);
- Consideration of the value of the Maternity Passport for other groups of parents/parents-to-be.

An advisory group met three times throughout the project with representation from a range of experts by profession (e.g. midwives and advocates for people with learning disabilities) and the expert by experience on the project. The group advised on the development/refinement of the Together Project resources.

Student midwives at the University of Surrey were also consulted to inform the refinement of project resources. Student midwives in their second year spent two hours reviewing the Together Project Toolkit and Maternity Passport, discussing their views of the resources with an expert by experience and giving their feedback individually and in small groups.

Dissemination

Based on my research in the field of learning disabilities and maternity care, I was invited to co-author a book 'Having a Baby' for parents with learning disabilities in the 'Books Beyond Words' series (an award-winning independent charitable publisher). This resource features the Together Project resources and provides a link to the Together Project University of Surrey website. This book won the British Medical Association award for Patient Information, the judging panel commended our book as a "brilliant co-production between people with learning disabilities and those who support them, leading to this accessible and engaging resource. It is well designed to fulfil its aims to support people with learning disabilities explore feelings about pregnancy and childbirth."

<https://booksbeyondwords.co.uk/news/2022/6/10/having-a-baby-wins-prestigious-bma-plgs-patient-information-award>

Dissemination via oral presentations:

- MidSoc conference, University of Surrey – May 2022;
- University of Exeter, 'Managing Complexity' module to student nurses – June 2022 & March 2023;
- Mencap's community of interest group 'people with a learning disability who are parents' – July 2022;
- Health Education England's South East Alternatively Able Programme Board – September 2022;
- ARC KSS Autumn Symposium: Spotlight on Research – September 2022;
- Workforce Organisation and Wellbeing Theme meeting within the School of Health Sciences at the University of Surrey – September 2022;



- Pre-presentation, 7% (11/158) conference attendees reported they felt competent or expert in preparing someone with learning disabilities for parenthood; this increased to 75% (112/149) post presentation.
- Pre-presentation, 12% (19/156) conference attendees reported they felt competent or expert in supporting someone with learning disabilities to parenthood and beyond; this increased to 75% (114/151) post presentation.

In addition, I have met with Becca Randell, Kent, Surrey and Sussex Implementation Lead to discuss routes to impact. Subsequently, Becca has scheduled a meeting with Prof Rowena Merritt to discuss development of a policy brief on the Together Project.

