



The Together Project

Understanding and improving support for
parents with learning disabilities

Dr Anna Cox

Mr Scott Watkin (BEM), Dr Athena Ip, Professor Cath Taylor
(and a wealth of wonderful advisors including people with learning disabilities)

1 to 2% of babies are born to a parent with learning disabilities



I feel let
down by
maternity
services



Better health and care for all
Health and care services for people with learning disabilities

"Mothers with learning disabilities and their babies are at higher risk than other mothers of poor outcomes during pregnancy and afterwards. They are more likely to have their children taken into care due to child protection or welfare concerns..."

....Some mothers may go through a formal assessment of their parenting skills and should be supported by maternity services to give them the best possible chance of passing the assessment"

Better Health and Care for All, NIHR 2020

Midwives say they lack knowledge and experience of learning disabilities



I want support to meet the needs of parents-to-be with learning disabilities

Together Project – Phase 1



Aim:

To develop a Toolkit for the maternity services workforce to more effectively support women and their families who have learning disabilities.

Scott, expert-by-experience

Phase 1 – Together Project



**Existing policy, guidelines,
research and resources**



**Stories of parents with
learning disabilities and
their carers (n=4)**



**Experiences of health and
social care professionals
(n=12)**









Identifying need

Preparing for parenthood

Supporting the journey to baby and beyond

Resource 1 – Toolkit for staff in maternity services

Introduction 	An introduction to the Together Project Toolkit and its contents
Identifying needs 	A practice discussion, actions, and questions for reflection addressing: ‘How will I know if the parent I am caring for has a learning disability and how will I identify their needs?’
Preparing for parenthood 	A practice discussion, actions, and questions for reflection addressing: ‘How can I prepare people with a learning disability to be the best parents they can be?’
Supporting the journey 	A practice discussion, actions, and questions for reflection addressing: ‘How can I work in partnership with parents with learning disabilities to support and enable them throughout their journey to becoming parents and beyond?’
Together Values 	The values underpinning the Together Project Toolkit <i>To print and display</i> 

Resource 2 – Maternity Passport for parents with LDs



This is my Maternity Passport

My name is: _____

I like to be known as: _____

My date of birth is: _____

My baby is due on: _____

About me and
my pregnancy

Getting ready to
be a parent

The support I need



- ☒ Please complete this Maternity Passport with support from your midwife
- ☒ Please keep this Maternity Passport with your handheld notes
- ☒ Please take this Maternity Passport to all your maternity appointments

I have been supported in learning the following practical tasks (please enter date of initial demonstration, dates when I tried to do this myself and indicate whether I can now do this by myself):

Task	Demo	1st Try	2nd Try	3rd Try	I can do it by myself Yes/No
Holding and Calming baby					
Nappy Changing					
Bathing					
Bottle Feeding					
Breast Feeding					
Changing Clothes					
Belly Button care					
Safe sleeping					

I visited the labour ward on (give date if applicable)

.....

.....

I was offered the choice of visiting the Special Care Baby Unit: **Yes/No**

I visited the Special Care Baby Unit on (give date if applicable)

.....

.....

I met my health visitor on (give date if applicable)

.....

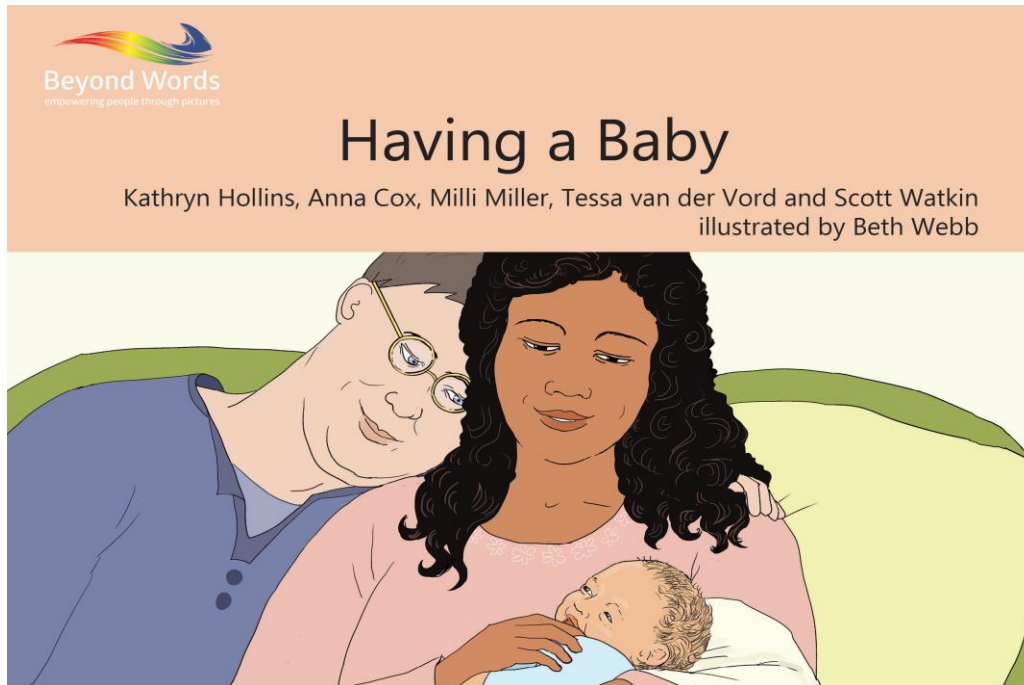
.....

Experts by experience gave us their views on the Maternity Passport

<https://youtu.be/TtH4W7psPOs>



Dissemination of Together Project resources



The book won
the British
Medical
Association
award
for Patient
Information 😊



Together Project – Phase 2



Elfrida Society, experts-by-experience

#uniofsurrey

Aim:

To explore the acceptability and perceived impact of Together Project resources in maternity services.

NIHR | Applied Research Collaboration
Kent, Surrey and Sussex

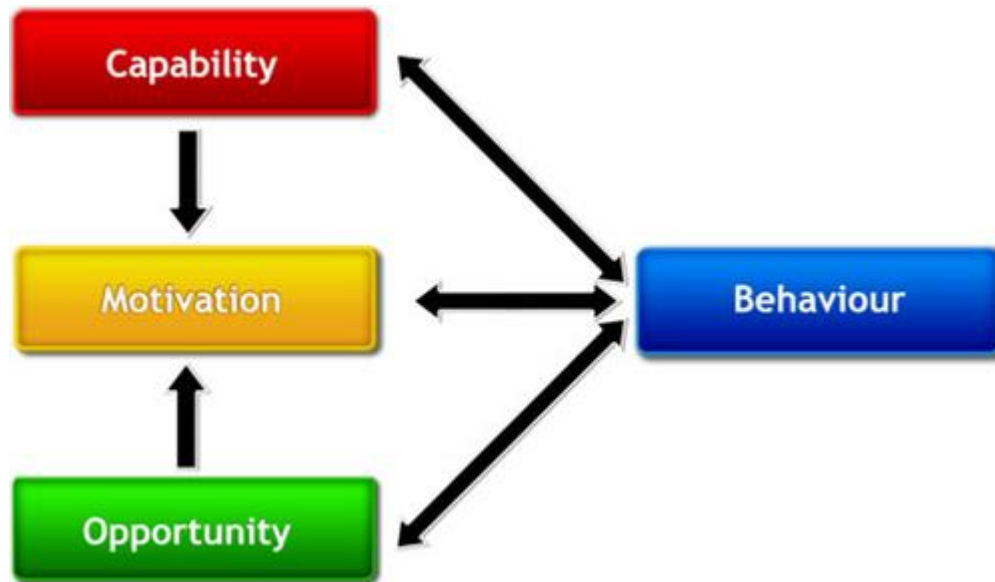
Phase 2 – Together Project

We asked midwives in four NHS Trusts to use our resources with parents-to-be with learning disabilities

We interviewed 17 midwives and 6 parents with learning disabilities to gather their views and experiences



Analysis – in progress



- Interview data - analysed inductively using thematic analysis;
- Themes generated and mapped onto the constructs from the COM-B model using a deductive approach, to understand the role of capability, opportunity, and motivation on implementation of the Together Project resources.

The COM-B system—A framework for understanding behaviour (Michie et al., 2011)

Next steps: Based on Together Project findings, we are making an educational film



NIHR | Clinical Research Network
Kent, Surrey and Sussex

A Specialist Midwife gave us her view of the Maternity Passport



Your feedback

If you would like to know more about the Together Project or download our resources, go to our website:

<https://www.surrey.ac.uk/together-project-resources-questionnaire>

We would be delighted to hear your feedback
(a.cox@surrey.ac.uk)



Acknowledgements



NIHR ARC and Health Education England fund this project; our advisors who bring a depth and breath of experience to guide the Together Project and the development of resources; and the parents and professionals who generously spoke to us about their experiences.



Thank you for listening