

Improving maternity care and experience for parents with learning disabilities

Despite national directives to improve the maternity care for people with learning disabilities, the maternity experience of these parents is often poor and lacks reasonable adjustment to care.

In response, the Together Project, led by the University of Surrey co-produced resources to support good maternity care for people with learning disabilities. The Together Project has been funded by Health Education England, the National Institute for Health and Care Research (NIHR) Applied Research Collaboration Kent, Surrey and Sussex (ARC KSS), and the NIHR Clinical Research Network Kent, Surrey and Sussex (CRN KSS).

Through co-production with professionals and parents the following resources were developed: -

The Together Toolkit for professionals working in maternity services, to support the delivery of good care for people with learning disabilities during their pregnancy.

A Maternity Passport to be held by people with learning disabilities who are pregnant and to include the relevant information needed by the professionals who support them.

An educational film that features advice and guidance from experts (by profession or experience) to support professionals working in maternity services to recognise when a parent-to-be may have learning disabilities.

"The maternity passport was like a breath of fresh airI can actually see something similar benefitting anyone who struggles with a mental health difficulty" (midwife)

"maternity services were quite scary... they didn't really understand people with learning disabilities..... we were worried that they would judge us and take our daughter away" (parent)

"I feel like I should get treated equal and not judged who I am" (parent)

UNIVERSITY OF SURREY

NHS Health Education England

The Together Project

Add a photograph of yourself here if you'd like to

This is my Maternity Passport

My name is

My date of birth is

My baby is due on

About me and my pregnancy

Getting ready for my baby

The support I need

Please complete this Maternity Passport with support from your midwife

Please keep this Maternity Passport somewhere safe

Please take this Maternity Passport to all your maternity appointments

NIHR | National Institute for Health and Care Research

7 essential elements to recognise and support parents with learning disabilities:-

- Increase learning disability awareness
- Adopt a positive mindset
- Build trust
- Respectfully ascertain need
- Reach out for specialist support
- Consider advocacy needs
- Make reasonable adjustments

Leading the research, Dr Anna Cox, Senior Lecturer in Health and Social Care, School of Health Sciences at the University of Surrey, said:

"The Together Project highlights 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. Together, we have created three resources which that are relevant and meaningful to the population they intend to benefit."

Ambitions going forward

The research team has also worked with parents with learning disabilities to adapt an existing tool to measure self-efficacy in the ante natal period. An accessible outcome measure is necessary to ensure that the support delivered to people with learning disabilities when they are expecting a baby, continues to be evaluated and improved.

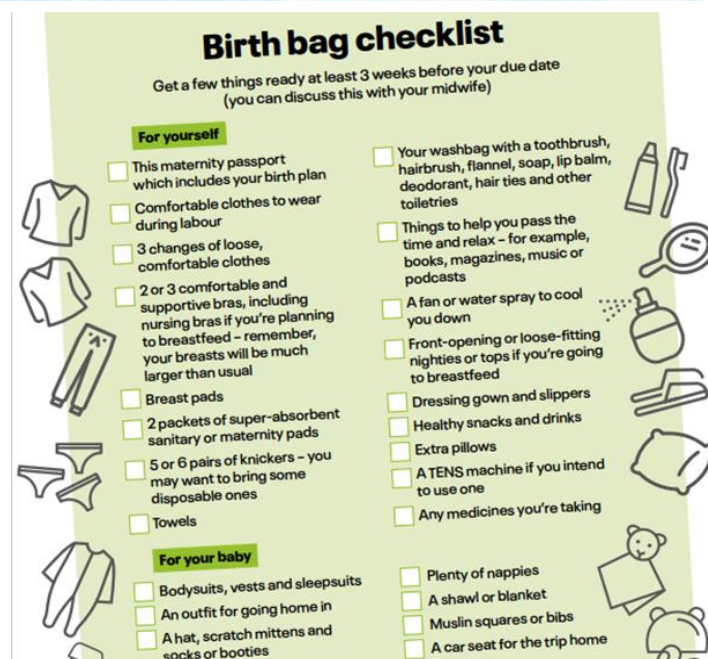
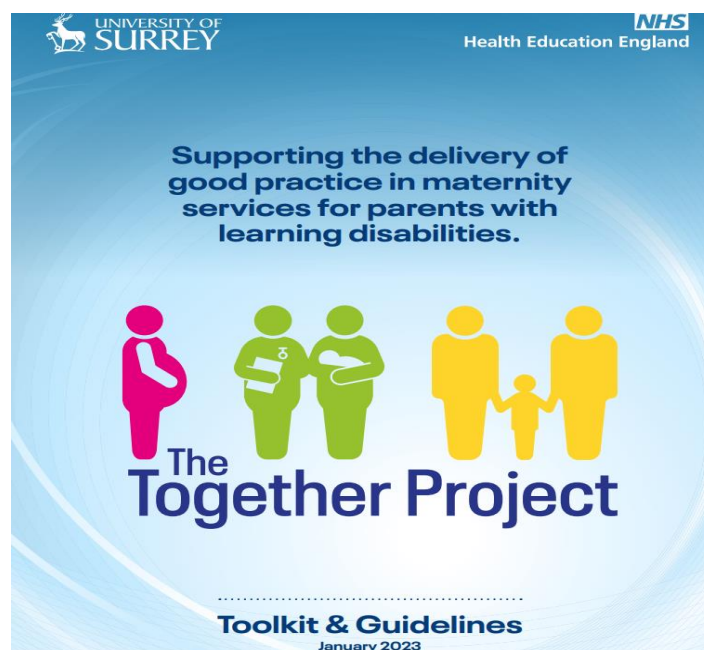
ARC KSS will be working with the Research Team at University of Sussex to develop a policy brief and share this with NHS England, Integrated Care Boards and key national professional bodies.

Resources including the toolkit, maternity passport and educational video will be shared across health and social care organisations nationally.

Further information and copies of maternity passport, toolkit and video:-

The Together Project: supporting the delivery of good practice in maternity services for parents with learning disabilities | University of Surrey

For information on ARC KSS Starting Well: Children and Young People's Mental Health Research [Starting Well: Children's Mental Health](#)



This research was funded by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration Kent, Surrey and Sussex. The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

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