

# The Together Project

Supporting the Delivery of Good Practice in Maternity  
Services for Parents with Learning Disabilities



## EXECUTIVE SUMMARY

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## **Project Team:**

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## **Advisory Group:**

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**Note regarding terms within the document:**

Throughout this document we use the terms ‘learning disability’ and ‘learning disabilities’. This can be substituted by ‘intellectual disability’ and ‘intellectual disabilities’.

Mencap’s definition of a learning disability is a broad, inclusive definition that was recommended by our advisory group. It states:

*‘A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life’ (Mencap 2020)*

The term ‘parent’ is used to refer to both current and expectant parents.

The term ‘Informal Supporter/Carer’ is used to refer to a person who supports or cares for the parent with a learning disability. This could be a family member, friend, neighbour or other person known to the parent with a learning disability.

## **Background:**

There are over 1.5 million people with learning disabilities in the UK. Despite entitlements to good health and social care service, many experience inequalities in provision. This is particularly pronounced in relation to maternity services. Despite directives to improve maternity care in general, and to improve care for parents with learning disabilities, quality of care is variable and the experience of parents with learning disabilities is often poor and lacking reasonable adjustments to care. Previous research reveals that professionals working with parents with learning disabilities often lack competence and confidence to respond adequately to their needs.

## **Research aims and objectives:**

The aim of the project was to develop a Toolkit for the maternity services workforce to more effectively support parents who have learning disabilities. The objectives were: (1) To identify and evaluate policy, guidelines, research and resources that relate to maternity care for parents with learning disabilities; (2) To collect the stories of parents with learning disabilities: what is their experience? And what are their views of 'what good looks like' in maternity care for parents with learning disabilities; (3) To explore health and social care professionals' experiences of working with parents with learning disabilities and what they perceive as challenges and opportunities to delivering care well; (4) To co-produce guidelines for 'what good should look like' for the workforce and people supported by the workforce using both the experiences collected and existing relevant research; and (5) To translate the co-produced guidelines into a Toolkit and pilot it in a small sample of the maternity workforce to determine whether it is 'fit for purpose'.

## **Research design:**

This project was designed as a mixed-methods service evaluation project, collecting data from an online survey and qualitative interviews with parents with learning disabilities and professionals who support them on the journey to parenthood and beyond. The project was underpinned by Appreciative Inquiry, an approach that focuses on identifying and building on good practice to further enhance services and organisations.

The inclusion of people with learning disabilities in both the project team and in the advisory group ensured that the Together Project was co-produced to be relevant and targeted to the issues of importance for parents with learning disabilities.

### **Findings:**

A total of 16 key stakeholders were interviewed regarding their experience of maternity care: six health care professionals, six social care professionals, two parents with learning disabilities, and two informal supporters/carers of parents with learning disabilities. These interviews were transcribed and thematically analysed (Braun and Clarke 2006). No complete responses were received to our online survey.

An overall finding of our analysis is the insight that good maternity care for parents with learning disabilities requires ‘A positive and proactive approach to identifying need; Reasonable adjustments to communication and providing information; and Professionals working together to support and enable parents.’

Three descriptive themes, each with sub-themes, were constructed and support this overall finding: (i) *Identifying need* (requiring awareness of learning disabilities; thinking beyond existing diagnoses; assuming a positive attitude; and asking key questions); (ii) *Preparing for parenthood* (adjusting communication and information to meet individual needs of parents with learning disabilities; and adjusting time and space so parents are not rushed when information is shared and their engagement is meaningful); (iii) *Supporting the journey to baby and beyond* (emphasising the importance of professionals working together; of building trust with parents; identifying and filling gaps in support needed by parents; and enabling parents to have a voice and be involved in decision making).

Existing guidelines, research and resources that relate to maternity care for parents with learning disabilities were scoped and synthesised with the findings from our analysis. This informed the collaborative development of a Toolkit and a Maternity Passport to support the maternity workforce to more effectively identify, prepare, and support people with learning disabilities for parenthood.

The Toolkit and Maternity Passport were piloted with 20 health and social care professionals. Views were sought regarding the acceptability, appropriateness and adoption of the resources. Feedback was given via survey (16 responses) and a discussion

group (4 attendees). Resources were also reviewed and refined by our Experts by Experience, and the Together Project Advisory Group.

### **Discussion:**

Findings from this service evaluation – the Together Project – confirmed that there are deficits in the maternity care of parents with disabilities. The successful co-production of the Toolkit was an output from the project and contains guidelines, actions and reflective questions to support the maternity services workforce. The Together Project delivered an additional resource within the confines of the allocated budget and time-line, the Maternity Passport. This was developed in response to needs identified in our data.

The Together Project sought key stakeholders' views of 'good' maternity care services for parents with learning disabilities. Health and Social Care Professionals were able to identify barriers to the delivery of good care to parents with learning disabilities. The first - and arguably the most significant - barrier was felt to be how to identify whether a parent has learning disabilities. Midwives reported feeling unprepared and unsupported to identify which parents have learning disabilities. The need for learning disabilities training was emphasised, as it has been in previous studies (Malouf, McLeish et al. 2017), and the value of learning disability training pre-registration was reflected on by participants.

Strategies to identify whether a parent has learning disabilities were shared and have been included in the Toolkit, but our data suggest that the barrier is broader than knowing the right question to ask. Interviews suggest some professionals are uncomfortable asking whether one or both parents have learning disabilities. We propose that practitioners would benefit from an opportunity to engage with parents with learning disabilities, to gain insight into how it feels to be asked, or not asked, important questions regarding their disabilities.

Our interviews with parents with learning disabilities and their informal supporters/carers provide further evidence that parents with learning disabilities experience negative perceptions of their capabilities as parents (Walsh-Gallagher, Sinclair et al. 2012, Gould and Dodd 2014, Malouf, McLeish et al. 2017, Theodore, Foulds et al. 2018). Unless a positive mindset towards the potential capabilities of parents with learning disabilities is adopted, it is likely that an avoidance of services and reluctance to disclose learning disabilities will

continue. People with learning disabilities value a workforce with a positive attitude (Davies and Matuska 2018), how to support and sustain this attitude requires deeper exploration.

Together Project participants reported that suitable information resources were not always available for parents with learning disabilities. This is contrary to legal requirements and recommendations (Office for Disability Issues 2011, NHS England 2015, Public Health England 2016, NHS England 2017) but supports previous research reporting a lack of accessible information in maternity services (Patient Experience Network & Change 2015, Homeyard and Patelarou 2018). The Toolkit provides maternity services with the details of resources considered accessible by participants.

As in previous research, time was commonly cited as a barrier to preparing people with learning disabilities for parenthood (Tarleton, Ward et al. 2006, Castell and Stenfert Kroese 2016). A specialist role in learning disabilities within maternity services may be one way of offering extra time to parents with learning disabilities.

Our findings suggest that electronic records are not best practice for parents with learning disabilities who may find paper notes more accessible. The Together Project has produced a Maternity Passport to be completed with and held by parents with learning disabilities. This will enable consistent and individualised information sharing with professionals, as well as informal supporters/carers.

Health and social care professionals are an important element of the support circle for parents with learning disabilities, but our findings suggest that inter-professional working and communication could be improved upon. Inter-professional collaboration is essential as it is associated with positive outcomes for parents (Aunos and Pacheco 2013, Castell and Stenfert Kroese 2016). The Maternity Passport seeks to support inter-professional collaboration by enabling each professional to see who else is involved in a parent's support circle and to understand what has, or has not, been discussed with them. The Maternity Passport will also support identification of gaps in support to alert professionals to necessary referrals.

Relational continuity is thought to contribute to a positive birth experience for women generally (Dahlberg and Aune 2013), and as such is recommended within 'Better Births' (National Maternity Review 2016). There are challenges to the continuity of care model

(Taylor, Cross-Sudworth et al. 2019) but our findings suggest that this should be considered best practice for women with learning disabilities, acknowledging that trust could be more challenging for parents with learning disabilities who may be fearful of losing custody of their child (Höglund and Larsson 2013, Sheerin, Keenan et al. 2013).

Parents with learning disabilities are less likely to raise their children than parents without disabilities. There are many factors that may inhibit a parent with learning disability from flourishing as a parent, and not all are able to succeed. But it should not be assumed that parents with learning disabilities will be unable to raise their child well, the focus should be on enabling parents with learning disabilities to be the best they can be, while safeguarding the interests of their child/ren. Those parents who do lose custody of their child/ren will require professionals to have appropriate knowledge and skills to respond effectively to their grief, but our findings suggest that this experience is currently unsupported.

### **Conclusion:**

The Together Project resources have been designed to build on and support the delivery of good practice and warrant further evaluation within maternity services to: determine their impact on the decision-making processes and behaviour of professionals working in maternity services; explore the barriers and facilitators to the implementation of resources; and evaluate the effect of resources on staff and parents with learning disabilities.

The next stage of the Together Project is essential to ensure that our good work leads to positive impact in the delivery and experience of maternity services. If parents with learning disabilities continue to receive standard preparation for parenthood, they are being denied a fair opportunity to succeed at raising their child/ren.

The values within the Together Project Toolkit pave the way for more a values-based approach to the development of authentic partnerships with parents with learning disabilities. In most situations, it will be possible for parents and professionals to work together effectively so that parents can be the best they can be. Enacting the Toolkit values will support ethical practice. The TOGETHER project values are: **T**rust; **O**pen-mindedness; **G**entleness; **E**nablement; **T**ime; **H**umility; **E**quality; and **R**espect.

## References:

Aunos, M. and L. Pacheco (2013). "Changing Perspective: Workers' Perceptions of Inter-Agency Collaboration With Parents With an Intellectual Disability." *Journal of Public Child Welfare* 7(5): 658-674.

Braun, V. and V. Clarke (2006). "Using thematic analysis in psychology." *Qualitative research in psychology* 3(2): 77-101.

Castell, E. and B. Stenfert Kroese (2016). "Midwives experiences of caring for women with learning disabilities - A qualitative study." *Midwifery* 36: 35-42.

Dahlberg, U. and I. Aune (2013). "The woman's birth experience—The effect of interpersonal relationships and continuity of care." *Midwifery* 29(4): 407-415.

Davies, J. and G. Matuska (2018). "Workforce development: perspectives from people with learning disabilities." *Tizard learning disability review* 23(4): 165–172.

Gould, S. and K. Dodd (2014). "'Normal people can have a child but disability can't': the experiences of mothers with mild learning disabilities who have had their children removed." *British Journal of Learning Disabilities* 42(1): 25-35.

Höglund, B. and M. Larsson (2013). "Struggling for motherhood with an intellectual disability--a qualitative study of women's experiences in Sweden." *Midwifery* 29(6): 698-704.

Homeyard, C. and E. Patelarou (2018). "To what extent are midwives adapting antenatal information for pregnant women with intellectual disabilities? A survey of NHS trusts in England." *Public Health* 158: 25-30.

Mencap (2020). Learning disability explained. Retrieved from <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>

Malouf, R., J. McLeish, S. Ryan, R. Gray and M. Redshaw (2017). "'We both just wanted to be normal parents': a qualitative study of the experience of maternity care for women with learning disability." *Bmj Open* 7(3).

National Maternity Review (2016). BETTER BIRTHS, Improving Outcomes Of Maternity Services In England. .

NHS England (2015). Patients and information SCCI605 Accessible Information specification. London.

NHS England (2017). Patients and information DCB1605 Accessible Information. London.

Office for Disability Issues (2011). Equality Act 2010: Guidance., HM Government.

Patient Experience Network & Change (2015). Celebrating the best of the maternity experience of care with a focus on parents with learning disabilities.

Public Health England (2016). People with learning disabilities in England 2015: Main report. London, PHE.

Sheerin, F. K., P. M. Keenan and D. Lawler (2013). "Mothers with intellectual disabilities: interactions with children and family services in Ireland." *British Journal of Learning Disabilities* 41(3): 189-196.

Tarleton, B., L. Ward and J. Howarth (2006). Finding the right support? A review of issues and positive practice in supporting parents with learning difficulties and their children. T. B. Foundation. London

Taylor, B., F. Cross-Sudworth, L. Goodwin, S. Kenyon and C. MacArthur (2019). "Midwives' perspectives of continuity based working in the UK: A cross-sectional survey" *Midwifery* 75: 127-137.

Theodore, K., D. Foulds, P. Wilshaw, A. Colborne, J. Lee, L. Mallaghan, M. Cooper and J. Skelton (2018). "'We want to be parents like everybody else': stories of parents with learning disabilities." *International Journal of Developmental Disabilities* 64(3): 184-194.

Walsh-Gallagher, D., M. Sinclair and R. McConkey (2012). "The ambiguity of disabled women's experiences of pregnancy, childbirth and motherhood: A phenomenological understanding." *Midwifery* 28(2): 156-162.