



Learning disability awareness training for student midwives

Guidance for midwifery educators



Contents

Foreword	03
Executive summary	04
1.0 Introduction	05
2.0 Developing collaborations	06
2.1 What we did	06
2.2 What we recommend	06
3.0 Co-producing training	07
3.1 What we did	07
3.2 What we recommend	08
4.0 Co-delivering training	09
4.1 What we did	09
4.2 What we recommend	12
5.0 Evaluating training	13
5.1 What we did	13
5.2 What we recommend	13

6.0 A values-based approach	14
7.0 Conclusion	16
8.0 Acknowledgements	17
9.0 References	18
Appendix 1 – Scott’s story	19
Appendix 2 – Co-production ground rules	22
Appendix 3 – Letter to student midwives	23
Appendix 4 – Ground rules for a positive learning experience	24
Appendix 5 – Mind Map 1	25
Appendix 6 – Mind Map 2	26
Appendix 7 – Mind Map 3	27
Appendix 8 – Facilitator’s guide	28



Foreword

In 2019, I was invited to be part of the Together Project to help understand and improve maternity care for people with learning disabilities.

During the project, my story ([appendix 1](#)) has been used as an example of both the good and bad elements of clinical practice. My story highlights the misconceptions that healthcare professionals formed about me and the challenges I had to overcome to prove I could be a good parent. My daughter is now 9 years old and is still being cared for and loved by both her parents, just as she should be.

The Together Project is the start of greatness to come. We have co-produced resources to support midwives to communicate with parents with learning disabilities and we have used these resources in learning disability awareness training for student midwives.

The Together Project resources and training can help midwives to ask the right questions and create good relationships with the parents they support.

I would love all universities that train student midwives to implement the Together Project training and resources. Student feedback has shown it will make a big difference to the way they practise when they qualify, which will hopefully mean that people with learning disabilities get the preparation and support they need to be good parents.

Our training and resources were co-produced with people with learning disabilities but can be used to improve the support given to other groups. If you're getting maternity care right for people with a learning disability, you're getting it right for everyone!

Scott Watkin BEM

Scott is a father with learning disabilities and a member of the Together Project team. In 2017, Scott was awarded the British Empire Medal (BEM) for his contribution to the learning disability community.

“I would love all universities that train student midwives to implement the Together Project training and resources.”

Scott Watkin BEM

Executive summary



Together Project trainers

Background

The National Maternity Review, 'Better Births' (National Maternity Review 2016) set out the vision for a maternity service in England that improves outcomes and reduces inequalities. However, Together Project research found that for people with learning disabilities, equity of maternity care is hindered by a maternity workforce who report lacking the competence and confidence to support parents with learning disabilities (Cox, Parsons et al. 2021, Cox, Ip et al. 2024).

The training

We have co-produced, co-delivered and evaluated learning disability awareness training for undergraduate midwifery students. This training aimed to equip student midwives with the skills and confidence to support people with learning disabilities to be the best parents they can be, from the very start of their professional careers. The training had a profound impact on University of Surrey students, and it was a positive experience for the people with learning disabilities who co-produced and co-delivered it (Cox et al. 2024).

This guide

In this guide, we present what we did and what we recommend within four stages: developing collaborations; co-producing training; co-delivering training; and evaluating training. We provide evidence-based recommendations to support academic and midwifery leads to introduce learning disability awareness training within their midwifery programmes. The guide can be used to inform the development of new collaborations and the co-production of new learning disability awareness training, or it may be used to implement and evaluate the Together Project learning disability awareness training. We recommend a values-based approach to developing and delivering training and to help with this, we present the **Together Project values** and how they were enacted as an example.

Potential impact

Inclusive and equitable maternity care should be fundamental, core components of midwifery training for all students, we suggest that the implementation of learning disability awareness training within higher education institutions can provide the essential foundation for the future midwifery workforce to overcome the inequity that currently exists in maternity services.

1.0 Introduction

People with learning disabilities¹ are particularly at risk of inequitable maternity care. They have poorer experiences of maternity services (Redshaw, Malouf et al. 2013, Malouf, McLeish et al. 2017), poorer outcomes (Tarasoff, Ravindran et al. 2020), and are more likely to have their children taken into care than those without learning disabilities (Booth, Booth et al. 2005, NIHR 2020).

People with learning disabilities may flourish as parents when support and services are personalised to meet their needs, but this is dependent on midwives possessing the skills and confidence to recognise and respond to their needs. Many parents with learning disabilities will experience a formal assessment of their parenting, and 'should be supported by maternity services to give them the best possible chance of passing the assessment' (NIHR 2020).

The Nursing and Midwifery Council standards of proficiency outline a midwife's role in supporting people with learning disabilities (Nursing and Midwifery Council 2019), but research highlights that midwives do not feel competent to identify or meet the needs of people with learning disabilities (Beake, Clark et al. 2013, Homeyard, Montgomery et al. 2016).

The Oliver McGowan Mandatory Training in Learning Disability and Autism has demonstrated a positive impact on the workforce (Department of Health and Social Care 2019), but professional development specific to maternity services is a valuable supplement, to ensure student midwives join the maternity workforce able to support the values and vision of personalised care.

The Together Project was inspired by the stories of parents with learning disabilities and existing research in the field highlighting inequity in maternity care. Learning disability awareness training for student midwives was conceived in collaboration with the Together Project's advisory group, consisting of experts by experience (people with learning disabilities), experts by profession (practitioners, support workers / advocates, academics and commissioners working in learning disabilities or maternity care) and student midwives. Advisors reiterated the need for, and endorsement of, maternity-specific training, focused on supporting equitable maternity care for people with learning disabilities.

Building on previous studies validating the inclusion of experts by experience in undergraduate health programmes (Happell, Platania-Phung et al. 2019, Happell, Waks et al. 2020, Goodhew, River et al. 2023), our research aimed to work with experts by experience (people with learning disabilities) to co-produce, co-deliver and evaluate learning disability awareness training for undergraduate midwifery students.

Our findings can be drawn upon by midwifery educators nationally and internationally who wish to implement maternity-specific learning disability awareness training to create an ethical learning culture which respects the principles of equality and diversity.

The development and evaluation of this training was funded by the NHSE Workforce Training and Education Directorate, South East Region, and includes resources developed using additional funding from 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).

➔ The Together Project is led by **Dr Anna Cox**, Senior Lecturer in Health and Social care at the University of Surrey.

Email: a.cox@surrey.ac.uk



¹ We use Mencap's definition of a learning disability, which is a broad, inclusive definition 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. (2024). "What is a learning disability?", from <https://www.mencap.org.uk/learning-disability-explained/what-learning-disability>.

2.0 Developing collaborations

2.1

What we did

The Together Project advisory group sign-posted the research team to learning disability organisations that provide support and advocacy within Surrey and London; areas sufficiently local to the University of Surrey that experts by experience could attend in-person co-production meetings and training days. Two organisations agreed to collaborate and invited people supported by their organisation to participate as experts by experience. The invitation included a Public Member Role Description (which outlined the role and expectations of experts by experience in their contributions to the project) adapted from the NIHR ARC form for public involvement. The description included that experts by experience would be thanked for their time and contribution in the form of a shopping voucher (Love2Shop), £25 per hour / £75 for a half day / £150 for a full day.

In addition, the Together Project researchers engaged with the Lead Midwife for Education and Director of Studies at the University of Surrey to ascertain the need for the training as well as explore any duplication within the existing midwifery programme.

2.2

What we recommend

- ☒ Include people with learning disabilities in an advisory group to ensure that innovations are developed that are relevant and targeted to the issues of importance to parents with learning disabilities (Cox et al. 2021).
- ☒ Collaborate with organisations who have established trusting relationships with people with learning disabilities to enable a supportive process of decision making and participation in research and training (Ip et al).
- ☒ Collaborate with academic institutions to organise the timing of training around the curriculum.
- ☒ Include experts by experience in the leadership of co-production projects, to support a valid sharing of power and insights into the reasonable adjustments needed to the process of co-production and co-delivery.
- ☒ Take time to consider accessibility and inclusivity for experts by experience, this could include an introductory film; easy read signposting; meeting rooms with minimal sensory stimulation; and a 'relaxation room' to facilitate time-out if required. Ensure that the setting feels welcoming and safe.
- ☒ Find out the daily routines and travel requirements for experts by experience and develop your co-production / training sessions around these timings.
- ☒ Support a sense of belonging for experts by experience (for example, provide a branded University jumper or lanyard to wear when delivering the training).

**"Atmosphere was welcoming,
it felt like a super safe space."**

[Advocate]



Together Project trainers with support worker

3.0 Co-producing training

3.1

What we did

Co-production team



Eight experts by experience agreed to attend monthly co-production meetings at the University of Surrey to develop learning disability awareness training for student midwives. Support workers and advocates from collaborating organisations attended these co-production meetings to support travel to and participation in the sessions. Experts by experience felt that their advocates understood their needs and had their best interests in mind, offering them downtime as necessary to make the best use of their energy levels. The co-production team were facilitated by the project leads, a senior lecturer in health and social care and a father with learning disabilities. This sharing of expertise and power supported an inclusive approach to co-production.

Co-production sessions



Learning disability awareness training was co-produced across six sessions. The first five sessions were held at the University of Surrey and the final session was held at the respective learning disability organisations to prepare for training delivery. These sessions focused on getting to know each other; how to identify if someone has a learning disability; how to recognise needs and make reasonable adjustments; how to support someone with a learning disability; and two sessions to practise training delivery. In line with NIHR guidance (NIHR 2021), at the first co-production meeting, the project leads facilitated the group to create co-production ground rules ([appendix 2](#)) to support the five essential elements of co-production.

An easy-read agenda was sent to each collaborating organisation a week before each session. Each member of the co-production team had their own folder to include the easy-read agenda for each meeting, minutes from previous meetings, communication aids, ground rules, and feedback forms. Feedback was sought from each member of the co-production team at the end of each session.



Co-producers reviewing the Together Project film

“Amazing how we’ve got to make that, to produce it, and how it was done. And I’m sort of proud that I’m being a part of it.”

[Expert by experience]

“Everyone felt included.”

[Expert by experience]

“I liked meeting new people and sharing stories.”

[Expert by experience]

3.2

What we recommend

- ✓ Establish ground rules for co-production to support an environment where all voices are heard, and individuals are treated with respect. Ground rules can help clarify expectations roles, responsibilities, and behaviours.
- ✓ Set clear objectives for co-production sessions, to support everyone to work with a purpose towards a shared goal.
- ✓ Allow time in the co-production process for team members to get to know each other (e.g. ice-breaking activities, celebration of life events), this is important in building trust and respect and supports the sharing of lived experiences and mutual learning opportunities.
- ✓ Break into smaller groups for discussion of topics that may be sensitive, to lessen anxiety compared to speaking out in larger groups. Consider other approaches to ensuring all voices are heard, such as using the traffic light system or the Makaton sign 'sharing' to highlight if voices are not being heard.
- ✓ Include support workers / advocates in co-production sessions to provide practical and emotional support to people with learning disabilities, to enable them to share their experiences.

- ✓ Clarify terminology and language during co-production sessions, so that it is clear what is preferred and acceptable, for consistency in training.
- ✓ Work in partnership with organisations to provide ongoing support to the co-production team.
- ✓ Offer sufficient opportunity to co-trainers to prepare for the sessions, to support their confidence and clarity ahead of training.

"I loved hearing people's experiences."
[Expert by experience]



Together Project co-production team

4.0 Co-delivering training

4.1

What we did

Training team



Seven experts by experience agreed to co-deliver the training they had co-produced. They worked in pairs with the support of their advocates and support workers. Training sessions were facilitated by Dr Anna Cox (project lead) and Scott Watkin BEM (father with learning disabilities).

Training sessions



The training was co-delivered across 10 sessions to over 100 student midwives at the University of Surrey. Training included online content for the student midwives to engage with individually prior to their training session and a three-hour in-person co-delivered training session. It was followed by a celebration event that included feedback from the training.



Together Project training team

Online content pre-training

Letter to student midwives

A letter to students introducing the training and inviting engagement with resources prior to their training session.

➔ [Click to see appendix 3](#)

Scott's story

Personal story of a parent with learning disabilities, highlighting how assumptions and actions can impact on transition to parenthood. Students were asked to reflect on what could have been done differently to support a positive experience of maternity care.



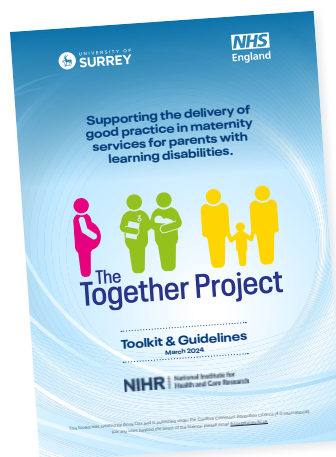
➔ [Click to see appendix 1](#)

Together Project resources

Students were asked to read two Together Project resources in advance of the training:

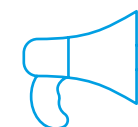
The Together Toolkit for professionals working in maternity services (including guidelines, an action checklist, and questions for reflection);

The Maternity Passport for parents who prefer an accessible personalised maternity care plan (to include information needed by the professionals who support them).



➔ [Download the Together Toolkit](#)

➔ [Download the Maternity Passport](#)



Channel 5 News report "Time was stolen from us"

A news broadcast reporting the high numbers of parents with disabilities who have their babies taken into care. The news report includes a mother with learning disabilities who supported the Together Project: X (formerly Twitter) post Channel 5 News "Time was stolen from us".

➔ [Click to see the X post](#)



Introductory videos of experts by experience

Co-trainers with learning disabilities created short introductory films for students to watch before the training.

Ground rules for a positive learning experience

Co-produced ground rules were shared with students and trainers to encourage respect, positive communication, and patience.

➔ [Click to see appendix 4](#)



In-person training content



The Together Project educational film

Students watched the Together Project educational film, in which experts (by profession or by experience) highlight how to sensitively and respectfully recognise when a parent has learning disabilities and how to support their needs. Scott Watkin, a father with learning disabilities, facilitated reflections on the film.

→ [Download the Together Project educational film](#)



Interactive information session

Experts by experience delivered this session using three mind maps they had created in co-production sessions.

Mind map 1: Get to know me and my needs ([appendix 5](#))

Mind map 2: Make reasonable adjustments ([appendix 6](#))

Mind map 3: Support me ([appendix 7](#))

Facilitators, support workers / advocates had a facilitator guide ([appendix 8](#)) and were able to offer support as requested by the trainers.



Role playing session

Students were given an opportunity to practise offering the Maternity Passport to co-trainers with learning disabilities, with feedback on their communication style and approach. The project lead (senior lecturer in health and social care) or midwife provided a demonstration before offering each student a turn.



Questions and reflections

Students were encouraged to think about what they had learnt from the training and what they would now do differently in practice. This was also an opportunity for students to ask questions post-training, to consolidate their learning.



Celebration and thanks

Experts by experience gave each student a certificate and thanked them for their commitment to improving practice. The contribution of experts by experience to training student midwives to provide equitable maternity care was also celebrated.

4.2

What we recommend

“Mind maps were good reminders which helped keep flow.”

[Expert by experience]

- ✓ Work with experts by experience to establish ground rules for a positive learning experience to share with students, to support sensitivity and respect for co-trainers with learning disabilities.
- ✓ Recognise that students may feel vulnerable and reassure them that the training is a safe place to improve their learning disability competence.
- ✓ Share personal stories of maternity care with students prior to training to highlight the challenges people with learning disabilities face in current practice, and trigger reflections on why the training is necessary and what improvements can be made.
- ✓ Invite people with learning disabilities to record introductory videos for students prior to the training, this may reduce barriers to communication and understanding.
- ✓ Consider the ratio of experts by experience to students in each group and its impact on engagement and experience. Splitting into smaller groups for role playing or discussions may be beneficial.
- ✓ Give experts by experience choice over who they train in partnership with, existing relationships or shared experiences may provide extra support and reassurance.
- ✓ Provide support workers / advocates who are present in training with a facilitator’s guide to enable them to prompt and support the experts by experience as needed.
- ✓ Schedule downtime into the training day for experts by experience, make it a social and enjoyable experience rather than exhausting.
- ✓ Ensure experts by experience feel valued for their contribution and thank them for their time and commitment.
- ✓ Celebrate the investment of students and experts by experience in the pursuit of equitable maternity care.

“Discussions were organic, fluid and inclusive.”

[Advocate]

“I really enjoyed the role play and discussions we had today.”

[Expert by experience]

5.0 Evaluating training

5.1

What we did

The evaluation is reported in an article in Nurse Education Today ‘Learning disability awareness training for undergraduate midwifery students: Evaluation of a co-produced and co-delivered educational intervention in England’ (Cox et al. 2024).

In brief, the impact and acceptability of the learning disability awareness training was evaluated using multi-methods: a pre-post training survey (students) and qualitative interviews (experts by experience).

The student survey was informed by the evaluation of mandatory Oliver McGowan training for staff working in health and social care (National Development Team for Inclusion 2022) and the experts by experience who co-produced and co-delivered the training. Findings indicate that the training had a profound impact on the students who took part at the University of Surrey, and it was a positive experience for people with learning disabilities who co-produced and co-delivered the training.

“I think this training should be taught next year and all the years after that. I feel it is important.”

[Student midwife]

“I now feel more confident in knowing how to start the conversation with someone with a learning disability and how to make reasonable adjustments to suit people’s individual needs.”

[Student midwife]

“Please keep doing these workshops to spread the word it only helps the next generation of health professionals be more educated and aware.”

[Student midwife]

5.2

What we recommend

- ☒ Collect and respond to feedback from experts by experience and support workers / advocates after each co-production / training session and make improvements ahead of subsequent sessions.
- ☒ Online surveys at three time-points allow for the progressive measurement of student midwives’ confidence in recognising and supporting people with learning disabilities.
- ☒ Collect student feedback at the end of the training to understand how training will shape their clinical practice going forward.
- ☒ Invite experts by experience to take part in an interview to understand their experience of developing and delivering training.



6.0 A values-based approach

The overall conduct of the project was informed by the Together Project values:

Trust; Open-mindedness; Gentleness; Enablement; Time; Humility; Equality; and Respect.

These values supported reasonable adjustments to the process of co-production and co-delivery of training.



Trust

The Together Project team built on existing trusted relationships through collaborating with organisations who supported experts by experience and including support workers / advocates from these organisations in the co-production and training sessions.

Trust was further developed within the group (comprised of experts by experience from two organisations) by making time to get to know each other, ensuring every expert by experience was heard and valued, and responding to feedback to ensure needs were met within the group.



Open-mindedness

The project was co-led by a father with learning disabilities who focused on shattering assumptions and encouraging open-mindedness, using his own achievements as an example of how much people with learning disabilities can achieve.

The Together Project training facilitated the adoption of a strengths-based approach and avoidance of assumptions and discrimination.



Gentleness

A gentle and considered approach was taken to welcoming people with learning disabilities to the University of Surrey. Accessibility needs were collected and addressed and an introductory film was shared to alleviate anxiety regarding an unfamiliar setting.

The training highlighted the need for professionals to enact gentleness and compassion in their practice, as parents with learning disabilities may be fearful of losing their child.



Enablement

NHS England advice was followed to make co-production and training sessions accessible and inclusive. This included ensuring all agenda and meeting notes were available in different formats, including easy read, and sent out with plenty of time for consideration.

During the meetings, communication was clear, without the use of jargon. Experts by experience were encouraged to have a voice, to make choices, and to contribute to training content.

During the training delivery, trainers worked in pairs and had choice over which content to present and who to co-present with.

6.0 A values-based approach



Time

The timing of co-production and training sessions were planned to be inclusive of the needs of the experts by experience.

The start time of sessions was adjusted to accommodate time for breakfast, school drop offs and travel to the University. Set breaks were scheduled to allow downtime for trainers. Time was taken to ensure experts by experience felt comfortable.

Students were encouraged to take their time when talking with people with learning disabilities, to support good communication.



Humility

Student midwives were asked to embrace humility and the mutual learning experience by listening to the individual needs and experiences of people with learning disabilities.

The consistent use of the term 'expert by experience' reinforced to students that both professionals and those with lived experience have expertise in how good maternity care should be delivered.



Equality

The key focus of the Together Project is to address inequity in maternity care. The training was designed to prepare midwives to deliver equitable and personalised maternity care from the very start of their professional practice.

The legislation underpinning equality was presented to students by the experts by experience directly and within the educational film shared as one element of the training.



Respect

Ground rules were used to create a culture of respect. Co-production ground rules ensured that the co-production team listened to each other's stories, respected each other's privacy and were non-judgemental.

Ground rules for learning with an expert by experience directed students to show respect for trainers with learning disabilities, and each other.

Respect for the valued contribution of experts by experience was demonstrated by thanking them for their time with vouchers, and creating a culture of belonging by offering branded lanyards and jumpers.

7.0 Conclusion

The Together Project at the University of Surrey has co-produced, co-delivered and evaluated learning disability awareness training for student midwives.

This guidance document has provided details of the process and the resources involved in developing and delivering the training.

You can access the paper outlining the evaluation of the training in an article in Nurse Education Today 'Learning disability awareness training for undergraduate midwifery students: Evaluation of a co-produced and co-delivered educational intervention in England' (Cox et al. 2024).

The Together Project team at the University of Surrey welcomes other higher education institutions to include this training within their current curriculums to support the future midwifery workforce to have the competence and confidence to deliver personalised and equitable maternity care to people with learning disabilities and other underserved populations.

Our hope is that we can join forces with other university partners to enhance our training evaluation. If you do implement training with support from this guide, please do let us know so that we can work in collaboration with a common goal of supporting equitable maternity care.

→ Please send your feedback on this organisational guidance and how you have used it to **Dr Anna Cox**.

Email: a.cox@surrey.ac.uk



Celebrating the success of the Together Project training with Surrey Choices and midwifery students



8.0 Acknowledgements

This research was funded by NHSE Workforce Training and Education Directorate, South East Region. This research would not have been possible without the experts by experience who co-produced and co-delivered the learning disability awareness training and the advocates and support workers from the Efrida Society and Active Prospects, who enabled them to take part.

We are also grateful to collaborators and members of our advisory group whose time, expertise and generosity informed this study. Dr Athena Ip assisted with developing the materials and gaining ethical approval for this study. The learning disability awareness training for student midwives included resources that were developed and evaluated with funding from the NIHR ARC KSS and NIHR CRN KSS.

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.

Made with Photosymbols.



9.0 References

Beake, S., L. L. Clark, T. Turner and D. Bick (2013). "A mixed methods study to develop and pilot a competency assessment tool to support midwifery care of women with intellectual disabilities." *Nurse Educ Today* 33(8): 901-906.

Booth, T., W. Booth and D. McConnell (2005). "The Prevalence and Outcomes of Care Proceedings Involving Parents with Learning Difficulties in the Family Courts." *Journal of Applied Research in Intellectual Disabilities* 18(1): 7-17.

Cox, A., A. Ip, S. Watkin, G. Matuska, S. Bunford, A. Gallagher and C. Taylor (2024). "Implementing and evaluating resources to support good maternity care for parents with learning disabilities: A qualitative feasibility study in England." *Midwifery* 133: 104001.

Cox, A., T. Parsons, S. Watkin and A. Gallagher (2021). "Supporting the delivery of good maternity care for parents with learning disabilities." *Midwifery* 102: 103073.

Cox A, Tobutt D, Harris J, Watkin S, Eynon C, Matuska G (2024). "Learning disability awareness training for undergraduate midwifery students: Multi-method evaluation of a co-produced and co-delivered educational intervention in England." *Nurse Education Today*.

Department of Health and Social Care. (2019). "Learning disability and autism training for health and care staff." Retrieved 08.02.2023, 2023, from <https://www.gov.uk/government/consultations/learning-disability-and-autism-training-for-health-and-care-staff>

Goodhew, M., J. River, Y. Samuel, C. Gough, K. Street, C. Gilford, N. Cutler and F. Orr (2023). "Learning that cannot come from a book: An evaluation of an undergraduate alcohol and other drugs subject co-produced with experts by experience." *International Journal of Mental Health Nursing* 32(2): 446-457.

Happell, B., C. Platania-Phung, B. Scholz, J. Bocking, A. Horgan, F. Manning, R. Doody, E. Hals, A. Granerud, M. Lahti, J. Pullo, A. Vatula, J. Koski, K. J. van der Vaart, J. Allon, M. Griffin, S. Russell, L. MacGabhann, E. Bjornsson and P. Biering (2019). "Changing attitudes: The impact of Expert by Experience involvement in Mental Health Nursing Education: An international survey study." *International Journal of Mental Health Nursing* 28(2): 480-491.

Happell, B., S. Waks, A. Horgan, S. Greaney, F. Manning, J. Goodwin, J. Bocking, B. Scholz, E. Hals, A. Granerud, R. Doody, C. Platania-Phung, M. Griffin, S. Russell, L. MacGabhann, J. Pulli, A. Vatula, G. Browne, K. J. van der Vaart, J. Allon, E. Bjornsson, H. Ellilä, M. Lahti and P. Biering (2020). "It is much more real when it comes from them": The role of experts by experience in the integration of mental health nursing theory and practice." *Perspectives in Psychiatric Care* 56(4): 811-819.

Homeyard, C., E. Montgomery, D. Chinn and E. Patelarou (2016). "Current evidence on antenatal care provision for women with intellectual disabilities: A systematic review." *Midwifery* 32: 45-57.

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): e015526.

National Development Team for Inclusion (2022). Evaluation of the Oliver McGowan Mandatory Training Trial in Learning Disability and Autism – Final Report.

National Maternity Review. (2016). "Better births, improving outcomes of maternity services in England.", from <https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf>

NIHR. (2020). "Better Health and Care for All." from <https://evidence.nihr.ac.uk/themedreview/better-health-and-care-for-all/>

NIHR. (2021). "Guidance on co-producing a research project." from <https://www.learningforinvolvement.org.uk/content/resource/nihr-guidance-on-co-producing-a-research-project/#:~:text=So%20what%20is%20co%2Dproduction,includin%20the%20generation%20of%20knowledge>

Nursing and Midwifery Council (2019). Standards of proficiency for midwives.

Redshaw, M., R. Malouf, H. Gao and R. Gray (2013). "Women with disability: the experience of maternity care during pregnancy, labour and birth and the postnatal period." *BMC Pregnancy and Childbirth* 13(1): 174.

Tarasoff, L. A., S. Ravindran, H. Malik, D. Salaeva and H. K. Brown (2020). "Maternal disability and risk for pregnancy, delivery, and postpartum complications: a systematic review and meta-analysis." *American Journal of Obstetrics and Gynecology* 222(1): 27.e21-27.e32.



Getting pregnant

In 2014, Scott's partner became pregnant. They had reached a mutual decision to have a baby and started trying. They were surprised at how quickly she became pregnant. They took six pregnancy tests to make sure that the result was accurate. Scott was shocked and he buried his head in the sand at first as it all happened so quickly. The next stage was letting their parents know. Scott's parents-in-law lived in Lincolnshire and his parents lived on the Isle of Wight. They were pleased to hear the news and were delighted they were going to be grandparents. Scott felt it would be wise to tell social services and his partner's social worker about the pregnancy; they took the news well and were supportive.

Antenatal care

At the booking appointment with the midwife, Scott's partner was immediately classed as "high risk" because she had a learning disability. The midwife did not explain what she was at high risk of, just told them "we do that for all vulnerable people". This made Scott feel very nervous. They did not see the booking midwife again.

The midwife Scott and his partner saw next time understood their situation better, as she herself had a child with learning disabilities. She became their named midwife. She understood where they were coming from. This midwife told Scott and his partner that she could not see a reason why they would not be able to parent their child. Scott felt this was positive.

The first part of their antenatal care went well in terms of information giving. However, it was given in a non-accessible format, with lots of medical jargon and was difficult for Scott and his partner to understand. They voiced to their midwife that they needed information in an accessible format. The midwife said that the hospital did not have the information in this format and the only place to obtain accessible information was from the organisation Change, which would charge

Scott and his partner to purchase it. Scott explained that this was not good enough and they needed the hospital to give them information in a way they could understand. Eventually, the hospital did give them accessible information. The midwife also gave them helpful practical tips to get the equipment together at home for the baby's arrival. The midwives were impressed that Scott and his partner were so prepared and gave them additional support to demonstrate how to use the equipment. Scott and his partner felt prepared to have the baby at the end of the pregnancy.

Scott feels that the issues started for them when their named midwife went off sick. The midwife they saw going forward did not understand them. They had to start from scratch explaining their situation and their needs. The midwife assumed that no reasonable adjustments would be required for the birth, whereas in fact reasonable adjustments could have had a big impact on their care and experience. Scott said it was difficult to get across their needs. For example, the midwife gave his partner a tour of the maternity unit to help signpost where to go in labour and promised that she was going to be present at the birth. However, when labour started, the midwife was not there. They assumed that they would have continuity and felt let down in labour.

Scott and his partner were referred to the safeguarding team for a "best interests meeting". Scott questioned why this meeting was taking place before the birth of the child. Scott felt that the safeguarding midwife ignored him during the meeting, she did not acknowledge him and focused only on his partner. This soured their relationship from the start. Scott said that they should have been treated as a family unit. Scott's partner needed support from him, they were in this together. Scott also felt that the safeguarding midwife couldn't make the reasonable adjustments to care they needed.

Intrapartum care

Scott's partner had a bloody show at 4am. Scott phoned the triage unit to inform them as neither Scott nor his partner knew what it meant. They had not been told it could happen. Scott wanted to take his partner to hospital. The midwife on the phone said, "yes, but you will probably be sent home". The midwife asked how much blood there was, but Scott couldn't answer accurately as it was in the toilet bowl. The midwife told Scott and his partner to come in. They had to get a taxi which was very expensive.

Appendix 1: Scott's story

Once in the triage unit, the midwife assessed Scott's partner and concluded that it was Braxton Hicks and early labour; they said she would be better going back home. Scott and his partner got the bus home as it was now morning and buses were running again. Scott was due into work and called to say that the baby was coming soon so was able to start his paternity leave that day. Throughout the day, Scott's partner started to become more distressed and to scream as labour progressed, disturbing the neighbours. Scott called the hospital again and explained that she needed to come back in. They got another expensive taxi back to triage.

Once they arrived in triage, it was three hours before Scott's partner was assessed again. She was in distress the whole time. The midwives said she was still in early labour and needed to go home. Scott said she cannot go home in this state. Scott was frustrated by the situation and left the unit to get some food. Whilst he was out, the midwifery team reviewed his partner's progress and called Scott to enquire where he was. Scott said that she needed to stay in hospital as that was where he felt she would get the best care. Scott felt that the maternity team did not like his response, and thought he was being irresponsible by not being present at the review. Scott felt that if he had not gone out of the hospital, the midwives would have forced him to take his partner home where she would have been distressed. So, he felt he had to leave in order for her to not be sent home, as the midwives would not send her home alone and so she would be kept in where she would receive the care she needed.

Scott did not go back to the unit that day. His partner stayed overnight but they talked on the phone a lot, both felt very emotional about the situation. Scott arrived at the maternity unit at 7am the next day and at 9am the decision was made to induce the baby due to the prolonged first stage of labour.

However, the induction did not start until 3pm that day, so Scott and his partner waited around for six hours, all that time she was in distress and pain. The midwives said that it was due to no capacity on the labour ward. Scott was crying as he did not like to see his partner in pain. The midwives gave her a TENS machine and Entonox but it was insufficient for her pain. She did not eat when food was offered as she was in so much distress.

Once the induction had started and Scott's partner's waters were broken, Scott felt the midwives were observing rather than intervening to get the baby out and he did not understand why; it made him question the care. Scott was crying as he could not cope anymore, he didn't feel he could fight anymore to make sure his partner received the care she needed, all the while watching her go through distress and pain.

Eventually Scott's partner had an epidural and was more comfortable. Scott overheard one of the doctors in the corridor saying "[Name] is screaming the hospital down, we need to get that baby out". This was when his partner had received her epidural and was no longer screaming in pain. This made Scott question the care that his partner was receiving and why they needed to deliver the baby quicker. Scott felt very upset as he could see that the staff did not understand how someone with Autism would experience labour.

Scott's partner delivered their baby vaginally and he was relieved and happy. Scott went home later that day. Whilst his partner was sleeping, the midwife took the baby away without telling her that she was going to do that, as the baby was fussing, probably with the intention to give mum some rest after the birth. However, Scott's partner woke up to find her baby gone all of a sudden. That was very scary for her and Scott.

After the birth

The safeguarding midwife had visited Scott and his partner on the postnatal ward the day after the birth for a "team around the family meeting". Scott's partner wanted to breastfeed, but felt the midwives observed, rather than practically supporting her to learn how to breastfeed. The safeguarding midwife said: "You can just bottle feed, Scott can go down the supermarket and buy the milk". Scott felt they had no choice. As a result, his partner ended up bottle feeding which was not her preference.

The safeguarding midwife asked about contraception. Scott's partner said that they did not use condoms. The midwife responded, "we will just give you the Depo injection". Scott felt that his partner thought she had no choice and had to accept what the midwife told her to do. The midwife did not explain the different types of contraceptives available or involve her in reaching an informed decision.

The safeguarding midwife also asked lots of questions, including "what would you do if the baby was unwell?". Scott answered that he would "call the GP or take her to A&E". The safeguarding midwife told him that his response was wrong, and that instead they should call the "midwifery team". Scott felt that his responses were sensible and not wrong, but she made out that he would not be able to look after the baby properly.

Preparing for discharge

Scott's partner had been in a side room during her stay on the postnatal ward. However, on the night before she was due to be discharged home, the midwifery team decided to move her to a bay in order for her to "interact with the other patients".

Before she was moved, the midwife on the dayshift suggested to double the baby's milk quantity for each bottle feed. This made the baby distressed overnight with possible colic. The midwife on the night shift questioned Scott's partner as to why she was giving the baby such a high quantity of milk, she explained it had been suggested by the dayshift midwife. However, this was not documented in the notes. Scott's partner felt that the nightshift midwife did not believe her despite the fact it had been said in front of Scott and his mother.

Unfortunately, this made the baby very unsettled, crying a lot during the night and disturbing other mums. During that first night in the bay, Scott's partner was accused of shaking the baby whilst trying to console her. They were not told who had said they observed it or when they said it had happened during that night. Scott thought perhaps some of the other patients may have complained about the baby crying to the midwifery team, who then felt that Scott's partner was not coping with a crying baby. This was understandably very upsetting for Scott's partner to hear. Scott was at home the following day (discharge day) getting the place ready and clean for when his partner and baby came home. His partner called to tell him what had happened, and that the midwives said they were going to put a referral into social services, but that they were allowed to take the baby home today as planned. Scott questioned this accusation as if the safeguarding team felt that their baby was in danger of being shaken, they wouldn't let them take the baby home that day.

Scott's partner's support worker came into hospital that day to take mother and baby home to Scott, who was waiting at home. The safeguarding midwife saw the support worker in the corridor and shouted sensitive information across to him, within earshot of two bays full of patients. She shouted, "[Name] is upset that we think she will shake the baby, and we have put a referral into social services". This was humiliating for Scott's partner to hear, as the other patients / partners / visitors were now aware of the accusation.

At home

One week later, children's services visited Scott and his partner at home. Lots of people attended this meeting: Scott, his partner, her support worker, the midwife, a family centre representative, and children's services. They informed Scott and his partner that the midwifery team felt that they could not cope with looking after a child because they had learning disabilities. Scott said that felt horrible to hear. He was also going through his father being seriously ill in intensive care in London, who he needed to visit urgently on the mainland, but he felt he could not disclose this to the team as that could make things worse.

In the meeting, Scott asked whether the team had heard of the government white paper which talks about how people with learning disabilities have a right to have a family, a job and to live independently. They replied, no, they hadn't. Scott advised them to read it. Scott also informed them that he is the co-national director for learning disabilities, representing policy and promoting the right to be independent. Scott reinforced that he is capable to parent his baby. The team said that they still needed to do an assessment, which they did.

Six weeks later they had another meeting and the decision was reached that Scott and his partner were parenting the baby to the best of their ability and the case was closed. Scott said that for the first six weeks of their baby's life, they lived under constant scrutiny as a result of an accusation made on the postnatal ward. This affected their physical and mental wellbeing, as well as how they bonded with their baby.

This story was told to Together Project researchers by Scott. We are so grateful to Scott for his bravery in sharing his personal story.

Appendix 2: Co-production ground rules

Building relationships

Trust each other.
Be kind to each other.
Support each other.
Don't force relationships and respect boundaries.
Form a group (e.g. WhatsApp) but only if people want to.

Including everyone's views

Ask everyone for their view.
Take turns in the group to answer so no-one is left out.
Put your hand up or use a communication card if you want to share your view.
Don't speak over each other.

Respecting each other

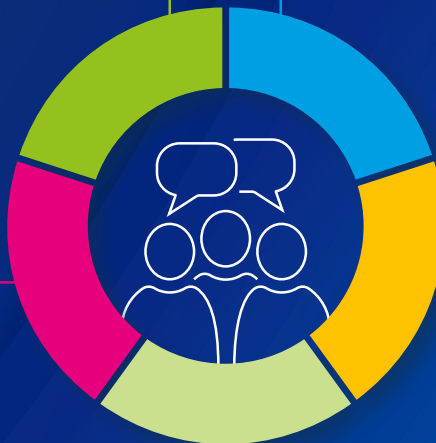
Protect people's privacy, don't use other people's names outside the group.
Don't judge people in the group.
Listen to each other's views.
Show commitment to each other and the work we are doing together.

Sharing power

Be aware that we are here to contribute whatever our role, we're all 'experts'.
Notice when someone has their hand up or a communication card and let them speak.
Use sign for 'sharing' if you think power needs to be shared.

Learning from each other

Be brave to share our stories (if we want to).
Don't make assumptions about people based on their diagnosis.
Remember that everyone is different and learns differently.



Appendix 3: Letter to student midwives



Dear student midwife,

We are a team of people, some of whom have lived experience of learning disabilities, who have worked together to co-produce learning disability awareness training for student midwives at the University of Surrey. We are looking forward to meeting you in your training session this month.

To make the most of this training opportunity, we would like you to allow yourself to imagine how maternity care could be transformed. We would like you to open your minds to the possibility that maternity care could be delivered differently for people with learning disabilities.

In your training session, you will meet at least one trainer with a learning disability, in addition to at least one academic member of staff from the School of Health Sciences. We will invite you to talk to the trainer/s with learning disabilities and reflect on their experiences. You may feel vulnerable in these discussions. You may worry that voicing your confusion and uncertainties regarding good maternity care for people with learning disabilities will expose you to be a less than perfect student midwife. Please be reassured that we are all in the same team and we are all working together to support the delivery of good maternity care. We hope you will join us in embracing humility and possibility.

In preparation for the learning disability awareness training, we would like you to engage with some films and reading:

- 1** Some of the trainers with learning disabilities have created short introductory films they would like you to watch before the training. Please watch the introductory films created by [Names]. These introductory films can be found in 'Prepare' on SurreyLearn.
- 2** In addition, one of the parents with a learning disability who co-produced this training was part of a Channel 5 news broadcast which reported the high numbers of parents with disabilities who have their babies taken into care: Twitter post Channel 5 News **"Time was stolen from us"**. We strongly recommend you watch this prior to the training, to help you to empathise with the fear of judgement that many parents with learning disabilities bring to maternity services.
- 3** The Together Project was initially inspired by the experience of Scott. Scott is part of the project team, and you will hopefully meet him in your training session. Scott has captured his experience of maternity services for you to read and reflect on before your training session. We would particularly like you to reflect on what could have been done differently to support Scott and his partner to have a positive experience of maternity services. You will have time within your training session to discuss your thoughts with other students in your group. Scott's story can also be found in 'Prepare' on SurreyLearn.
- 4** The Together Project team have also co-produced two resources to support the delivery of good maternity care for people with learning disabilities: The Together Toolkit for professionals working in maternity services (including guidelines, an action checklist, and questions for reflection), and the Maternity Passport to be held by people with learning disabilities who are pregnant (to include information needed by the professionals who support them).

Please look at these resources in preparation for your training session. The Together Toolkit and Maternity Passport can also be found in 'Prepare' on SurreyLearn.

We are really looking forward to learning with you.

The Together Project Team

Appendix 4: Ground rules for a positive learning experience

Co-produced ground rules were shared with students and trainers to encourage respect, positive communication, and patience.



Recognise how important this is to us

We want to make a difference.

We want to help you to give good maternity care to people with learning disabilities.

Some of us have had poor experiences of health and social care.



Enjoy the session with us

We are so pleased to have this opportunity.

Get to know us.

We might be nervous, make it a safe space for us to share our stories.

Please put away your mobile phone / laptop and stay in the moment with us.

Give us feedback, we want to know what we did well.



Show us respect

Treat us as your equal, don't label or judge us.

Give us a chance to speak, don't talk over us.

Listen to us.

Respect our choice if we don't feel comfortable discussing a topic.

Respect our privacy: our stories are important, but please don't share our names outside the session.



Use positive communication

Use respectful language.

Speak calmly and clearly.

Please use the communication cards if you would like to ask us a question or if something isn't clear.

Be kind to us, and to other students in the group.



Be patient with us

We may not always say things in a professional way.

Our speech might not always be clear.

If you would like us to repeat anything, please ask in a nice way.

If we don't understand your question, please repeat it in a way that will help us to understand you.

Learning with experts by experience

MIND MAP 1

Say who you are



1

Get to know me



2

Remember, I am a person not a 'case'



3

Remember, I have the right to have a family



4

Get to know me and my needs

Share something about you or your day



5

Don't assume I lack capacity to make decisions



6

Don't assume I won't bond with my child



7

Focus on my strengths



8

MIND MAP 2

Allow time



1

Don't talk too quickly



2

Stop and explain



3

Use words I can understand



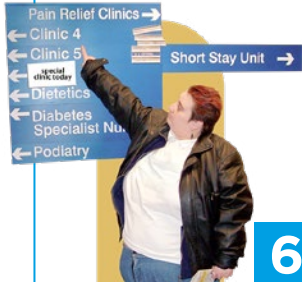
4

Consider my needs when deciding where to meet



5

Make it easy for me to find you



6

Make reasonable adjustments

Use my Maternity Passport



7

Don't make me re-tell my story



8

Offer me easy read with pictures



9

Speak to me directly and not through my supporter



10

Make decisions about me with me



11

MIND MAP 3

Ask me what support I need



1

Help me to be confident to say what I need



2

I may need people with me



3

Please include my family / friends



4

I need to build trust in people who support me



5

Support me

Help me understand who is involved in my care



6

Communicate well with other professionals



7

Give me practical support



8

Support me to birth and beyond



9

Appendix 8: Facilitator's guide

Facilitators and support workers / advocates who were present in the interactive information sessions were provided with this facilitator's guide, to enable them to prompt and support experts by experience as needed.

Mind map 1



1 Say who you are

At the beginning, say who you are. Trainers say who you are and invite students to say who they are. Remind students to always explain their job role and to give examples of what they do.



6 Don't assume I lack capacity to make decisions

Don't make assumptions and do something on my behalf, but instead just ask me what help I need, otherwise you cannot meet my needs. Ask sensitively as shown in the film.



2 Get to know me and my needs

Facilitators to invite trainers to open up about their story. Then, trainers to invite students to ask questions to trainers.



7 Don't assume I won't bond with my child

Don't assume I cannot bond with my child just because I have learning disabilities.



3 Remember I am a person not a 'case'

I am a person and have the right to be treated equally. I am not a 'case' for study. Please use empowering language.



8 Focus on my strengths

Highlight what I am doing well, help me to build my confidence.



4 We have the right to a family

I have the right to have a family and for that family to stay together, with the right support. Remind students of the Equality Act 2010.



5 Share something about your day

Be reciprocal to build trust. People with learning disabilities are more likely to open up about additional needs if trust has been built. Demonstrate this by encouraging trainers and students to take the time to get to know each other. Invite the students to open up and share something about their day to build a two-way conversation.

Mind map 2



1 Allow time

Under the Equality Act, you can request for a double appointment to allow more time. Please try to see me on time, I might get stressed waiting.



2 Don't talk too quickly

Speak clearly and not too quickly so that I can follow what you are saying.



3 Stop and explain

Take the time to stop and explain what you mean in a way that I can understand. Sometimes staff are too busy to stop and explain, let me know that I can stop you if I do not understand your explanation and support me to have the confidence to do so.



4 Use words I can understand

Don't use medical jargon, or medical words and expect me to know what it means. I might need further detail like examples to help me understand. Use words that I understand to explain what you mean.



5 Consider my needs when deciding where to meet

For example, ask me about how sensory issues affect me and whether I would benefit from a quiet room. Or how far I need to walk from the lift to the meeting room. Try and accommodate this as it could help me to communicate better. For example, 9am appointments are not practical, my advocate might not be available.



6 Make it easy for me to find you

Make sure it is easy and accessible for me to find you. You can help by meeting me at the entrance to help me to find you more easily. If I need step free access, make sure there is a lift. Remember that some people cannot read or are colour blind so hospital signs can be confusing.



7 Use my Maternity Passport

Don't forget that my Maternity Passport contains useful information and the reasonable adjustments I need. Check that I have one and help me to fill it out and make use of it.



8 Don't make me re-tell my story

Make sure you read my notes before my appointment. It is difficult (physically and / or emotionally) to re-tell my story over and over again. Be prepared and have everything to hand for the appointment.



9 Offer me easy read with pictures

Explain what you mean by easy read, don't make assumptions that students know what it is. Use easy read formats, especially with pictures to help encourage mutual understanding. If you don't have easy read to hand, find out where in your trust you can obtain it from, ask the learning disability nurse. The Together Toolkit provides links to sites / resources which can be used for signposting.



10 Speak to me directly and not through my supporter

Don't speak over me whilst speaking to my supporter. Speak to me directly. Work with carers, but don't leave me out.



11 Make decisions about me with me

Make sure to include me in decisions that are made about me, don't make decisions for me when I can do this myself. Within the Equality Act, there is a section 'Access to Information Act' which says that patients have the right to see information people have written about them in medical notes.

Mind map 3



1 Ask about what support I need

Don't be afraid to ask what support I need, don't just assume. You can also use my Maternity Passport to see if there are any gaps in support.



2 Help me to be confident to say what I need

I may need support to speak up for myself, without fear of my words being escalated or taken the wrong way.



3 I may need people with me

These could be partner, family, friends, advocate, support workers, or others. I may need them for emotional and / or practical support. This may mean allowing for more birth partners than usual. Please be accommodating.



4 Please include my family / friends

Recognise the support needs of me and my family. Communicate well with all of us. It is important that partners are included to promote equality in caring for the baby. This is so they have continuity, from a person outside maternity services.



5 I need to build trust in people who support me

It is helpful if I can see the same midwife so I can build trust. Establishing trust can be difficult for people with learning disabilities. Some people either trust too quickly or do not trust enough because they have been failed in the past.



6 Help me to understand who is involved in my care

Some people don't have a trusting relationship with social workers because of anxiety that their children may be taken away. Acknowledge that is a common anxiety and we need to support people to build a better relationship. Remind students to provide a clear explanation or an accessible information pack including what staff they may encounter and what that their role is in caring for parent and baby, so that they can understand in advance who is involved in their care.



7 Communicate well with other professionals

I will be supported best if everyone is on the same page. During handover, don't just relay what my disability is, also share what reasonable adjustments I need. A good relationship between the multidisciplinary team will help communication channels to be transparent.



8 Give me practical support

I may need support with practical life skills, such as caring for the baby, including demonstration of some basic parenting tasks to give me confidence.



9 Support me to birth and beyond

Postnatal care is just as important as antenatal care. Signpost to children's centres and postnatal classes for extra support. Build confidence, tell parents about third party support (charities, advocacy etc).



Authors

Dr Anna Cox
Mr Scott Watkin (BEM)
Ms Darya Tobutt
Ms Caroline Eynon
Mr George Matuska (RNLD)

Collaborators

Active Prospects
Elfrida Society

Copyright © 2024 University of Surrey.
This resource was created by Dr Anna Cox
and is available under a Creative Commons
Attribution Licence (4.0 International)

Please cite as: Cox, A., Watkin, S., Tobutt, D.,
Eynon, C., and Matuska, G. (2024). Learning disability
awareness training for student midwives: guidance
for midwifery educators. University of Surrey

