

A measure to evaluate parenting interventions: Using inclusive research to modify a tool to measure change in parenting self-efficacy during the antenatal period

Athena Ip¹  | Sally Kendall² | Ali Jabeen³ | Scott Watkin⁴ | Anna Cox¹ 

¹School of Health Sciences, University of Surrey, Guildford, UK

²Centre for Health Services Studies, University of Kent, Canterbury, UK

³Elfrida Society, London, UK

⁴Expert by Experience, UK

Correspondence

Anna Cox, School of Health Sciences, University of Surrey, Guildford, UK.
Email: a.cox@surrey.ac.uk

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Abstract

Background: With the right support, people with learning disabilities can be 'good enough' parents (Coren et al., 2011; Murphy & Feldman, 2002). Parenting programmes exist to support parents and are made accessible for people with learning disabilities who are expecting a baby, but evaluation of the benefit of these interventions is poor due to a lack of accessible outcome measures (May & Harris, 2020; Wade et al., 2008). The Tool to Measure Parenting Self-Efficacy in the antenatal period (TOPSE- ante-natal) measures the impact of parenting interventions on an individual's self-efficacy during the antenatal period. This study aimed to modify the TOPSE ante-natal tool through a process of inclusive research, to support a consistent approach to evaluating parenting interventions from the perspective of parents-to-be with learning disabilities.

Methods: A two-phase study using interviews and discussion groups was conducted in a process of inclusive research to modify the TOPSE ante-natal tool. Phase one involved conducting eight cognitive interviews (interviews to understand how individuals process and recall information) with parents with learning disabilities. These were conducted remotely via Microsoft Teams, transcribed verbatim and analysed using content analysis (Krippendorff, 2013). Participants were recruited using snowballing techniques through the advisory groups' networks. Phase two included three discussion groups with study collaborators and advisors ($n = 14$) to assess the accessibility and acceptability of adaptations of the tool, each making further refinements for consideration.

Findings: Interviews and discussion groups highlighted how parents-to-be with learning disabilities experienced some of the original TOPSE-ante-natal negative statements, including negative points on a Likert scale, difficult to comprehend. Figurative statements and unfamiliar words also caused confusion, and statements focussed on the pressures of parenting were experienced as confrontational by people with learning disabilities. Statements were removed or replaced and agreed

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upon in discussion groups to ensure that the tool was accessible and meaningful to people with learning disabilities.

Conclusions: We have used a process of inclusive research to modify a self-efficacy tool for parents-to-be with learning disabilities that is freely available on the TOPSE website (<https://www.topse.org.uk/site/>). The next steps are for this tool to be used and validated in future studies evaluating parenting interventions for people with learning disabilities. This will inform a knowledge base of what interventions should be used by practitioners who are supporting people with learning disabilities to prepare for parenthood.

KEYWORDS

inclusive research, learning disabilities, parenting interventions, self-efficacy

Accessible Summary

- People with learning disabilities may need support to be good parents.
- There are parenting programmes to support people with learning disabilities who are expecting a baby, but it is difficult to find out how helpful they are, as questionnaires to measure this are not accessible for people with learning disabilities.
- This article describes how we worked with parents with learning disabilities and advisors (advocates, researchers and health professionals) to make an accessible and meaningful version of a questionnaire.
- This questionnaire can be used to find out if and how parenting programmes help people with learning disabilities feel more confident in how they will parent their babies.

1 | BACKGROUND

It is estimated that there are 1.5 million people with a learning disability in the United Kingdom (Mencap, 2022) and more than 53,000 parents with learning disabilities in England (Working Together with Parents Network, 2008). Women with learning disabilities report a poorer experience of maternity care compared to women without a learning disability (Redshaw et al., 2013) and have to meet stricter criteria to demonstrate their capacity to parent (Tarleton & Ward, 2007). Furthermore, people with learning disabilities experience a higher rate of child protection or welfare concerns than other parents (Booth & Booth, 2005; Elvish et al., 2006; Wilson et al., 2014). Despite being commonly judged as inadequate parents (McConnell, 2002), they have been shown to be 'good enough' parents when provided with appropriate and sufficient support (Coren et al., 2011; Murphy & Feldman, 2002).

Systematic reviews of parent interventions offering tools and support for people with a learning disability (May & Harris, 2020; Wade et al., 2008) highlight that research in this area is limited and lacking rigour, calling for further studies in the area to provide robust evidence about which components of interventions are effective, for whom and for how long. Controlled evaluations of parenting

interventions are needed with a validated outcome measure and large representative samples to strengthen the evidence base.

Self-efficacy refers to an individual's perception of their ability to perform a task competently (Bandura, 1982). Parental self-efficacy is a powerful predictor of parenting behaviour (Coleman & Karraker, 1998). In 2005, the Tool to Measure Parenting Self-Efficacy (TOPSE) was created to evaluate parenting interventions in the postnatal period so that they could continue to be developed and improved (Kendall & Bloomfield, 2005). TOPSE has already been used in the evaluation of a number of parenting programmes (Bloomfield & Kendall, 2007) and has been modified for parents with learning disabilities (Bloomfield et al., 2010) to measure parenting self-efficacy for this target group in the postnatal period. In the study reporting the adaption of the TOPSE tool for use in the postnatal period, Bloomfield, Kendall and Fortuna report that participants were supported by a psychologist assistant to complete the TOPSE questionnaire and were invited to comment on their understanding and degree of help needed. The researchers found that the revised version of TOPSE took much less time and less help to complete than the standard version. The majority of the small sample of parents participating (11) found the revised statements understandable and liked the 'smiley face' layout of the responses.

The TOPSE-ante-natal measure (Ginja et al., 2018) was later developed to measure self-efficacy in the ante-natal period, adapted from the postnatal tool (Kendall & Bloomfield, 2005). This has been used in studies to evaluate the effectiveness of parenting interventions (Deave et al., 2019; Panza et al., 2020). However, this measure is yet to be made accessible for parents-to-be with learning disabilities to evaluate the success of ante-natal interventions and support. People with learning disabilities should receive intervention early in their journey to parenthood to support them in demonstrating their capacity to be a parent; therefore, tools to evaluate interventions in the ante-natal period may be even more valuable for this population.

Inclusive research seeks to fully involve people with learning disabilities in the research process. Challenges to inclusive research include tokenistic or unclarified involvement of people with learning disabilities or a misconception that people with learning disabilities are a homogeneous group (Blunt et al., 2012). The potential for a power imbalance between disabled and nondisabled contributors must be considered at all stages of the process and steps taken to support a sharing of power and inclusivity (Brooks et al., 2013). Overcoming challenges to inclusive research requires time and commitment, developing and drawing upon trusted relationships to support the meaningful involvement of people with learning disabilities. The inclusive process of this research study draws upon existing relationships with a range of people with learning disabilities and for some contributors, their previous involvement in research delivered by the research team (Cox et al., 2021).

2 | PRESENT STUDY

2.1 | Aim

This study aimed to modify the TOPSE ante-natal tool through a process of inclusive research, to support a consistent approach to evaluating parenting interventions from the perspective of parents-to-be with learning disabilities

2.2 | Patient and public involvement

The inclusion of people with learning disabilities in both the research team and the advisory group ensured that this study was co-produced to be relevant and meaningful to people with learning disabilities and that the adapted tool is accessible for parents-to-be with learning disabilities. An 'expert by experience' (father with learning disabilities) was a paid member of the research team who supported the need for the study and informed the development of the protocol, recruitment information and study materials. The advisory group was made up of parents/parents-to-be with learning disabilities; advocates for parents with learning disabilities; health and social care professionals working with people with learning disabilities; and academics specialising in learning disability research.

Each person brought different values to the group and contributed to the development of the final tool.

2.3 | Ethical approval

This study received a favourable ethical opinion from the University of Surrey Ethics Committee (UEC ref: FHMS 21-22 069 EGA).

2.4 | Study design

A two-phase study design was adopted using interviews and discussion groups in a process of inclusive research to modify the TOPSE ante-natal tool. We conducted cognitive interviews with parents with learning disabilities to adapt the existing tool (phase 1), followed by a series of focus groups with advisory group members to assess the accessibility and acceptability of the adapted tool and make further refinements (phase 2).

3 | METHODS AND FINDINGS

3.1 | Phase 1

3.1.1 | Methods

Cognitive interviews (interviews to understand how individuals process and recall information) were carried out with community-based parents with learning disabilities to adapt the existing tool (Ginja et al., 2018).

Participants: Participants were recruited via two advisory group members who worked as specialist advocates with parents with a learning disability. Parents/parents-to-be who were supported by the specialist advocates were invited to participate if they identified as having a learning disability; were expecting a baby or had at least one child under the age of five; their first language was English; and they had access to the internet as well as familiarity using online technology for remote interviews via Teams. Specialist advocates supported parents/parents-to-be to understand the study information and make a decision regarding participation; all identified potential participants were judged to have the capacity to consent.

3.1.2 | Recruitment procedure

Specialist advocates were provided with study packs that included accessible information for potential participants. The specialist advocates explained the purpose of the study and what it would involve using the printed easy-read information and/or playing a film of the study researcher reading the easy-read information. The information informed the parents that they were being invited to take part in an online interview. Potential participants were offered

the option of asking the specialist advocate to be present in the interview or a family member/friend. As an alternative or in addition, participants were offered the option of the expert by experience (a father with learning disabilities who was also a member of the research team) attending the interviews to offer support.

3.1.3 | Cognitive interviews

Before starting the online interview, the researcher shared their screen with the participant to explain the aims and objectives of the study and ensure that they understood their right to withdraw at any point during the interview without giving a reason. Participants were given an opportunity to ask any questions, their understanding was clarified and verbal consent was taken.

Cognitive interviews were carried out with two researchers (A. I., A. C.) present. Cognitive interviews are commonly used in questionnaire development to enhance face validity (Egger-Rainer, 2019) and have previously been used for adults with mild learning disabilities (Milne et al., 1999). They are useful for identifying areas in a questionnaire that need clarity and questions that are challenging for participants to understand and respond (Kamp et al., 2018). One researcher conducted the interview, while the other recorded information on an observation form for each statement including time taken to respond; clarification required; and signs/expressions of discomfort. If applicable, the role of the advocate was decided by the participant at the start of the interview; this flexibility sought to ensure that the process was not threatening to the participant. Demographic information was sought at the beginning of the interview, including the participants' age, gender, ethnicity and age of their children. The researcher shared statements from the TOPSE-ante-natal questionnaire (Ginja et al., 2018) one at a time in a large font with a scale indicating the level of agreement beneath it. Each statement was read aloud by the researcher and participants were asked to choose a number from 0 to 10 to indicate how much they agreed with each statement (0 'completely disagree' to 10 'completely agree'). The researcher regularly reassured the parent that some questions may be difficult to understand, and it was not a test; rather, they were experts by experience working with researchers to improve a research tool. Following their response to each statement, the researcher and/or advocate asked the parent why they had chosen that number (to determine any misunderstanding) and how they felt about responding to that statement (to determine any discomfort). If any misunderstanding or discomfort was determined, the researcher and/or advocate worked with the participant to reword the statement until they felt it was accessible and acceptable. All 36 statements were considered by each participant within six sections: emotion and affection; play and enjoyment; empathy and understanding; pressures; self-acceptance; and learning and knowledge.

Finally, the researcher shared the original version of the TOPSE-ante-natal questionnaire (Ginja et al., 2018) and asked the parents to give feedback on its layout and to provide any

recommendations to make it accessible. Parents were also shown the accessible version of the TOPSE parent questionnaire (Bloomfield et al., 2010) and asked to comment on what aspects of the layout they would recommend for the accessible version of the TOPSE-ante-natal questionnaire.

Participants were given the choice of a £15 Tesco or Amazon voucher as a thank you for taking part.

3.1.4 | Ethical considerations

Four specific considerations were addressed in collaboration with experts by experience: First, information-giving/informed consent for people with a learning disability. This involved providing accessible information on the study and an easy read consent form; information on the study was shared by a trusted professional to support potential participants to feel comfortable asking questions. Second, promoting inclusion and respecting those who declined participation. It was made clear on the Participant Information Sheet that participation was voluntary and that not participating would not lead to any negative consequences. Third, promoting benefit and minimising harm from participation. Participants were reminded at the start of the interview that they could stop the interview at any time, and the participant information sheet directed them to the learning disability helpline hosted by Mencap, if necessary. Participants were able to choose who was present to support them during the interview to ensure that the process was not threatening. It was emphasised that there were no right or wrong answers and that participants were not being assessed. Finally, the issue of confidentiality and exceptions to this were made clear on the participant information sheet so that any safeguarding issue would be acted on immediately using the University of Surrey's 'child protection and adults at risk' policy.

3.1.5 | Analysis

The transcripts were automatically generated via Teams and checked against the recording for accuracy. Data were analysed using a content analysis approach (Krippendorff, 2013). The researchers familiarised themselves with the transcripts and developed a coding framework consisting of the following categories: comprehension/confusion, comfort/discomfort and requested changes.

3.1.6 | Feedback

In total, eight cognitive interviews were carried out with parents with learning disabilities. The average age of the participants was 31 years, and the sample consisted of two fathers and six mothers (see Table 1 for demographic information). Interviews ranged from 51 to 76 min (mean duration = 64 min). The average time taken to complete the questionnaire was 30 min. The median scores for each of the six

TABLE 1 Participants' demographic information.

Ethnicity N %		
White British	4	50
Black British	3	37.5
Pakistani British	1	12.5
Sex		
Female	6	75
Male	2	25
Number of children		
1	4	50
2	1	12.5
3	1	12.5
4	1	12.5
5	1	12.5

scales were 57.3 (emotion and affection), 56 (play and enjoyment), 54 (empathy and understanding), 38.5 (pressures), 48.5 (self-acceptance) and 49 (learning and knowledge), with a total of 303.3 out of 360 (higher scores indicating higher self-efficacy) compared to 319 baseline scores for the original TOPSE-ante-natal with people without learning disabilities, respectively (Ginja et al., 2018).

Negatively phrased statements were most confusing to parents (e.g., 'I will find it hard to cuddle my baby') or statements including figurative speech (e.g., 'I will be able to put myself in my baby's shoes', and 'As a parent, I will be able to take most things in my stride'), who either struggled to answer at all or provided incongruent explanations for their responses. Statements including unfamiliar words also caused confusion (e.g., 'affection', 'confident', 'understand', 'relationship', 'potential', 'patiently', 'expectations', 'assert', 'pressure', 'ignore', 'manage' and 'overcome'), as did statements including abstract phrases (e.g., 'nice days', 'strong parent' and 'developmental changes'). Participants also found it more difficult to understand statements that did not begin with 'I' as the subject matter (e.g., 'When my baby is sad I will understand why') or used 'he/she' as a personal pronoun (e.g., 'I am confident my baby will be able to come to me if he/she is unhappy'). In addition, they found it difficult to answer statements that were open to interpretation and wanted examples; specifically, they sought clarity regarding who 'other people' referred to in statements as their response would be different depending on whether these people were professionals (e.g., 'I will be able to say "no" to other people if I don't agree with them').

Participants felt uncomfortable answering some statements and at times refused to answer; this was mostly related to statements under the 'pressure' section, with the majority of the respondents expressing discomfort with the statement 'I will not do that well as a parent'. Participants also expressed discomfort answering statements including comparison to other parents (e.g., 'I will manage the pressures of parenting as well as other parents do'). The phrase 'be able to' also caused discomfort and participants often wanted this removed from statements.

When asked about their views on the layout and design of the tool, participants reported not liking the 10-point Likert scale and would prefer to circle faces to indicate their level of agreement. They requested more colours, bigger font and bigger spaces between the statements.

3.1.7 | Revisions

Two researchers (A. I., A. C.) who conducted the interviews revised the questionnaire based on data from the eight cognitive interviews with parents with learning disabilities, creating draft 1 of the accessible tool. All six negative statements were changed to be positive; all statements were changed so that 'I' was the subject; statements that had the words 'he/she' were changed to 'they'; and 'be able to' was removed from statements. All unfamiliar words and abstract phrases were changed to suggestions made by parents during the interviews.

The questionnaire scale was changed to a 5-point scale with faces representing 'agree a lot', 'agree a bit', 'don't know', 'disagree a bit' and 'disagree a lot'. The faces were presented according to the traffic light system, with colours ranging from red 'disagree a lot' to green 'agree a lot' replacing the 10-point Likert scale. This was in line with the earlier accessible version of the TOPSE learning disability tool for post-natal parents (Bloomfield et al., 2010).

No statements were removed at this stage but those that had caused participants discomfort were highlighted for discussion in phase 2. Section headings were changed to become more meaningful for parents with learning disabilities, particularly changing words that participants found difficult to comprehend in the cognitive interviews. The section on 'emotion and affection' was changed to 'love and comfort', 'play and enjoyment' was not changed as parents found this easy to understand, 'empathy and understanding' was changed to 'understanding your baby', 'pressures' was changed to 'knowing what to do as a parent', 'self-acceptance' was changed to 'respecting yourself as a parent' and 'learning and knowledge' was changed to 'learning as a parent'. The headings were also changed to form a sentence stating what the section is about (e.g., 'This section is about love and comfort').

3.2 | Phase 2

Three discussion groups were conducted with study collaborators and advisors to assess the accessibility and acceptability of adaptations of the tool, each making further refinements for consideration.

3.2.1 | Discussion group 1

This involved a Professor of Community Nursing (S. K.) who developed the original TOPSE-ante-natal questionnaire (Ginja et al., 2018); a learning disability nurse; and an expert by experience

with learning disabilities (S. W.). Discussion group 1 reviewed draft 1 of the accessible tool.

Further amendments were made by discussion group 1 members, creating draft 2 of the accessible tool. These included changing the word 'recognise' to 'know' and 'calmly' to 'talk nicely' as discussion group members felt that these might be difficult for some parents to understand. In a statement including 'cuddle my baby', 'cuddle' was changed to 'comfort' as it was acknowledged that some people who have physical disabilities may find it difficult to hold or cuddle their baby. Where statements referred to 'help' or 'advice', this was changed to 'support'. In statements that included reference to 'other people', 'people' was changed to 'parents' to make it clear that the statement was not referring to professionals. Statements focussed on getting the baby to listen to them and listening to the baby were removed as discussion group members felt that this concept was covered in a later statement; furthermore, parents found it difficult to comprehend listening to a baby and suggested that it meant listening through a baby monitor. Discussion group members were in agreement that statements in the section on 'pressure' may be difficult for parents to complete as certain statements could be perceived as confrontational. All six statements in this section were removed and replaced with the following two statements: 'I will not take any notice of other parent's advice about parenting if I don't agree' and 'I will parent in the way I think is best for my baby'. Other statements were reworded to be framed more positively; the word 'enough' was removed from a statement so that it read 'I will be a good parent' and another statement of parenting was reworded to 'I will be as good as other parents'.

With regard to the layout of the tool, the team felt that the scale should be reversed starting with positive responses and working across to negative responses. They also provided suggestions about the faces chosen for the scale.

3.2.2 | Discussion group 2

This involved two specialist advocates for parents with a learning disability who supported recruitment in phase 1 (A. J.): a learning disability and autism lead in an NHS Trust/clinical advisor in learning disabilities for Health Education England and a clinical psychologist specialising in learning disabilities. Discussion group 2 reviewed draft 2 of the accessible tool.

Draft 2 of the accessible tool consisted of 27 statements. Discussion group 2 members suggested adding a facilitator guide so that if parents needed support with answering the questionnaire, facilitators would know to provide minimum input and to encourage the parents to answer for themselves as much as possible. It was also suggested that instructions should be provided for the parents, informing them about the purpose of the questionnaire and a sentence to let them know that everyone interprets concepts in different ways so as to answer according to what the statement means to them. Statements were further amended or removed; for example, 'I will know why my baby is sad' was removed as the group

felt that the question may be difficult to answer for anyone, with or without a learning disability. 'I will not take any notice of other parent's advice about parenting if I don't agree' was amended to 'I will know that it's okay to not agree with other parent's advice'. Discussion group 2 members felt that it was important to be more specific about the type of support being referred to; the statement 'I will solve most problems with a bit of support' was changed to include *the 'right' support* and two further statements were added: 'I will know who to reach out to for support' and 'I will ask for help from professionals if I need to'. These two statements were considered appropriate for people with learning disabilities within the section 'pressures'.

In addition, discussion team 2 suggested changing the colours of the faces on the Likert scale from the traffic light system, as it may deter people from choosing the red face at the negative end of the scale.

3.2.3 | Discussion group 3

This involved the specialist advocate for parents with a learning disability; five parents with learning disabilities; and a parent advocate. This was a hybrid meeting with four advisors attending in person and three attending via Zoom. Discussion group 3 reviewed draft 3 of the accessible tool. Advisors with learning disabilities were given the choice of a £15 Tesco or Amazon voucher as a thank you for their contribution to the discussion group.

Overall, discussion group 3 members approved draft 3 of the accessible tool. However, parents with learning disabilities in the group felt strongly that they would not respond to statements using the end of the scale, 'disagree a bit' or 'disagree a lot', as they perceived these to be negative. They felt that 'don't know' could replace these two options without making them feel uncomfortable and therefore the scale was changed to a three-point scale. They felt that 'agree a lot' should be in the colour green and so this was changed from blue to green (see Appendix 1 for the revised self-efficacy tool).

4 | DISCUSSION

We have conducted and described an inclusive study that modified the TOPSE ante-natal tool to support a consistent approach to evaluating parenting interventions from the perspective of parents-to-be with learning disabilities. Working with the target population is an integral part of constructing or adapting a questionnaire (Kooijmans et al., 2022; O'Keeffe et al., 2019); this modified tool reflects the views and experiences of parents with learning disabilities derived from cognitive interviews. Further refinements were made by study advisors, including parents with learning disabilities, advocates for parents with learning disabilities, a Professor of Community Nursing (S. K.) who developed the original TOPSE-ante-natal questionnaire, a learning disability and autism lead

in an NHS Trust, a clinical psychologist specialising in learning disabilities and a learning disability nurse. The breadth of experience in the research team and advisory group, and the focus on inclusivity and a sharing of power in the research process, have ensured that the tool is accessible and meaningful to parents-to-be with learning disabilities and those who support them; this is a core principle for research on learning disabilities (Bigby et al., 2014).

Evidence-based recommendations for the construction or adaptation of questionnaires for use by people with learning disabilities consider both the content and the format of questionnaires (Kooijmans et al., 2022). Evidence suggests that content should include simple vocabulary; use positive and active phrasing; and use the literal meaning of words (Bell et al., 2018; Vlot-van Anrooij et al., 2018). Our findings concur with and expand on these recommendations. We found that parents with learning disabilities objected to a scale that included negativity as they could not understand why someone would be negative toward their baby. When answering negatively phrased questions, the parents' explanation of why they had chosen the number on the scale often indicated a misunderstanding and showed that they had answered using the wrong direction of the scale. This supports previous research that found that using all positive questions may reduce the likelihood of respondents making mistakes (Sauro & Lewis, 2011). Our findings are also consistent with a previous study adapting the original TOPSE tool for parents with learning disabilities (Bloomfield et al., 2010) as they also highlighted how parents found negatively phrased statements difficult to comprehend and these were all changed to positive ones in the final tool. Furthermore, our findings were also concordant in terms of the need to change specific words that were unfamiliar to people with learning disabilities and to remove abstract phrases such as 'I am able to put myself in my child's shoes' that were also difficult for parents to understand in the previous study.

Our findings also concur with previous recommendations regarding the response format of questionnaires for use by people with learning disabilities (Kooijmans et al., 2022). The preferences expressed by the experts by experience included in this research lend support for a three-point scale to be used on questionnaires for use by people with learning disabilities (Cuthill et al., 2003; Fang et al., 2011; O'Keefe et al., 2019). Feedback on the layout of the tool was also consistent with findings from the study adapting the original TOPSE tool for parents with learning disabilities, which found that parents preferred faces over a numeric Likert scale, and larger font size (Bloomfield et al., 2010).

The original questionnaire required the most significant modifications within the section on 'pressures'. It is interesting but not surprising that parents with learning disabilities experienced this section as confrontational. It is notable that participants' parenting self-efficacy had the lowest mean score for the section on the 'pressures' of parenting, compared to other sections (meaning that parenting self-efficacy was highest in 'emotion and affection' and 'play and enjoyment'). In explanation, parents referred to previous experiences where they have had to deal with situations involving confrontation; for example, one parent spoke about having to assert

themselves with professionals when they were 'pushed out'. Discomfort with statements around 'pressures' may relate to the previous experience of judgement and stereotyping and being measured against harsher criteria than nondisabled parents, with consequences including having their child removed from their care (Wilson et al., 2014).

The section headings used on the accessible tool were changed to become more meaningful for parents with learning disabilities. The original section heading 'pressures' became 'knowing what to do as a parent', which was considered less confrontational. For people with learning disabilities, knowing what to do as a parent will most likely involve a greater involvement of support, so statements that included reaching out were added to this section: 'I will know who to reach out to for support' and 'I will ask for help from professionals if I need to'. Research shows that parents with learning disabilities can be 'good enough' parents when provided with the right support (Coren et al., 2011; Murphy & Feldman, 2002) and thus they should be empowered to 'reach out' when they need help.

As with all research, there were limitations to this study. One notable limitation is that we did not interview any people with learning disabilities who were expecting a baby. All participants had at least one child under the age of five; it would be useful to see the differences in scores between people with learning disabilities who are already parents and those who are expectant parents, as our participants had to recall back to when they were pregnant in order to respond to the statements. There is also the potential that response bias occurred as participants were given a £15 Tesco or Amazon voucher for their time taking part in the study; however, to mitigate this, we reminded the participants that there are no right or wrong answers and to give their reasoning after they had chosen a number on the scale to ensure that they understood the question and provided a number that reflected their response. Finally, this study has not validated the accessible version of the tool, although this tool is based on the original TOPSE tool, which is found to be a valid and reliable measure (Benzies et al., 2013; Kendall & Bloomfield, 2005). The recommended sample size to evaluate a scale (including tests of dimensionality, reliability and validity) is 10 respondents per survey item (Boateng et al., 2018); therefore, 240 respondents would be required to complete this scale at two time points to determine whether it continues to reliably measure self-efficacy as an underlying theoretical construct. This is a challenging sample size to achieve within this population. Initially, this accessible version of the TOPSE ante-natal tool will be validated in a similar way to the standard TOPSE tool (for use in the postnatal period) for people with a learning disability, reported by Bloomfield, Kendall and Fortuna in 2010. Testing the accessible TOPSE ante-natal tool for use with people with learning disabilities will rely on the degree of assistance required to complete the questionnaire and the level of understanding of the statements, within a small sample of people with learning disabilities who are expecting a baby.

A particular strength of this study was the involvement of specialist parent advocates in the recruitment process. Previous studies that have sought to recruit people with learning disabilities

(Becker et al., 2004; Iacono & Murray, 2003; Oliver et al., 2002), including the original TOPSE study in which the accessible version for parents with learning disabilities was developed (Bloomfield et al., 2010), have highlighted the challenges in terms of identifying people with learning disabilities, issues around consenting and confidentiality (Becker et al., 2004; Bloomfield et al., 2010; Iacono & Murray, 2003; Oliver et al., 2002). In this study, we were able to easily recruit a sufficient number of parents with learning disabilities as they had established trusting relationships with specialist parent advocates who discussed the study with the parent beforehand, informed them about confidentiality and supported them in making an informed decision regarding their participation, in line with convention on the rights of persons with disabilities (United Nations, 2006) before verbal consent was taken by researchers. Furthermore, their involvement allowed for continuity of support throughout the cognitive interviews if needed, which is important for people with learning disabilities.

5 | CONCLUSION

Research should be equitable in offering a broad spectrum of the population an opportunity to impact the delivery of health and social care; this requires the involvement of people with learning disabilities in research studies. Previous research has highlighted the barriers to including people with learning disabilities in research; this study reports an approach that facilitated and supported inclusive research. We have demonstrated that advocates play a vital role in supporting people with learning disabilities to have a voice in research. Together, we have created an accessible version of a parenting self-efficacy tool for use in the ante-natal period. The tool is designed to be used pre- and post-intervention to evaluate whether the intervention improved parenting self-efficacy. The next steps include further evaluation of the tool, to ensure that this modified version can be used in future research projects to evaluate parenting interventions for people with learning disabilities and for practitioners to use the tool with parents to identify areas where they may need more support.

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Theodore, clinical psychologist and senior lecturer, Royal Holloway University of London.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Anonymised data are available on request.

ORCID

Athena Ip  <http://orcid.org/0000-0002-8574-2569>

Anna Cox  <http://orcid.org/0000-0001-5254-1296>

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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