

PEER REVIEW HISTORY

BMJ Paediatrics Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Developing the FEEDS Toolkit of parent-delivered interventions for eating, drinking and swallowing difficulties in young children with neurodisability: Findings from a Delphi survey and stakeholder consultation workshops
AUTHORS	Taylor, Helen Pennington, lindsay Morris, Christopher Craig, Dawn McConachie, Helen Cadwgan, Jill Sellers, Diane Andrew, Morag Smith, Johanna Garland, Deborah McColl, Elaine Buswell, Charlotte Thomas, Julian Colver, Allan Parr, Jeremy

VERSION 1 – REVIEW

REVIEWER	Reviewer name: Mrs. Rebecca Davidson Institution and Country: NHS Lanarkshire, Speech and Language Therapy Competing interests: None
REVIEW RETURNED	31-Jan-2022

GENERAL COMMENTS	<p>This is a most welcome addition to the research for this cohort of children. Any clinical queries I had in regard to how such a toolkit could be implemented were addressed through the workshops undertaken. There was broad representation of professionals involved and it was reassuring to see that the child's voice was included as part of the research process. The information gained on parental vs professional priorities is fundamental for any clinician working in this field. A shared decision-making approach is critical and addressed well in this research project. It is reassuring to see the authors acknowledge that there is no 'one size fits all' approach to intervention for children with eating, drinking and swallowing difficulties. The remaining challenge is to know what the priorities and perceptions may be for the parents and carers who do not respond to professional interventions and research. A small concern with such a toolkit is how to ensure that novel and innovative, evidence-based practices be considered for any future editions. The only question which I didn't feel was fully addressed is the second question under the title 'What this study adds?' ie clarity on the interventions and outcomes to focus on within future research'. I'm hopeful that there will be an opportunity for further detailed research from the data gained into the difference in perceptions of which interventions are considered useful.</p>
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REVIEWER	Reviewer name: Dr. Melissa Gladstone Institution and Country: University of Liverpool, Department of Women and Children's Health Competing interests:
REVIEW RETURNED	12-Feb-2022

GENERAL COMMENTS	<p>FEEDS study BMJ Open review</p> <p>This paper describes a study which provides results of a consensus process looking at 1) which interventions parents of children with neurodisability and professionals feel may be helpful for children with neurodisabilities who have eating, drinking or swallowing difficulties (EDSD) and 2) what outcomes should be being measured for children who are provided with interventions for EDSD.</p> <p>This is a useful paper which will practically be helpful to professionals who are interested in having a toolkit of options for supporting children with neurodisabilities who have EDSD. Generally, this paper could be accepted but there are a few points that might strengthen it for the reader.</p> <p>Abstract</p> <p>The abstract might benefit by describing the numbers of parents and health professionals sampled.</p> <p>Introduction:</p> <p>Should neurodisability be defined? And in relation to this, should there be any mention of whether children with AFRID are taken into account in this article or not – just to clarify – as it is something that many in the field are discussing presently.</p> <p>Methods</p> <p>It may be worthwhile just reviewing an article which provides some guidelines on reporting on Delphi and consensus studies https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6500274/ and consider referencing it for this paper. Generally the guidelines are followed and it is clear how many participants took part in the survey and there is a clear criteria for dropping items as well as for defining consensus (>67%) with each stakeholder group needing to rate an intervention or outcome as essential (rated 7-9 at round 2). It is not clear whether there was any other "stopping criteria" rather than the rounds – a sentence on this might be worth adding. Could the authors explain why they chose >67%?</p> <p>The authors provide a little more information in this paper about exactly how the original survey was sent around and what kinds of parents tended to take part. This may be because it is referenced in other papers, however for this paper, it would be good to reiterate what the criteria for identifying participants was and whether this was reproducible and how participants were selected and excluded.</p> <p>Interventions chosen to go into Delphi:</p> <p>It is not entirely clear how the original interventions and ideas from parents were chosen to go into the Delphi – were they all included in the Delphi or only some and how was this chosen?</p> <p>The interventions provided are quite wide e.g. modifying environment or modifying position – was any more detail given at this stage to parents as to what types of interventions they could consider or come up with?</p> <p>Outcomes chosen to go into Delphi:</p> <p>How were outcomes in this survey prioritised? Were all outcomes previously identified prioritised?</p> <p>Were the 15 parents and 19 professionals all from the local surrounds? How were they chosen or did they choose themselves? Could you provide a little more demographic and specific information about this group – maybe specific diagnoses of children might add a bit and maybe age of parents and sociodemographics?</p> <p>Procedure for group work:</p> <p>Were notes taken verbatim? How were they analysed thematically? Were there frameworks used? Were they done by hand? Were specific tools such as NVIVO used? Were the notes transcribed after into a computer? Who did the thematic analysis? How did the team decide on key themes? Who was the research team who decided</p>
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	<p>this? A few additional details here might be helpful for the reader to understand the methodology and the rigour in the methodology at this stage.</p> <p>Table 4 – some of the table looks like it was literally moved from a programme for analysis in to a table and I wonder if the parts where it says “no missing data” should be removed?</p> <p>Results</p> <p>Some of the text relating to the parents views on interventions and outcomes for future research might be nice if provided as verbatim quotes – maybe as a box? Otherwise it is unclear as to whether this is results or your own discussion in this section.</p> <p>Limitations</p> <p>One limitation that may be worth mentioning is that this study was done at a time before COVID where sending texts and electronically interacting with parents was harder. Most parents and professionals, as far as I can tell, were recruited by being provided a paper version of a leaflet with a link to a website. It would be interesting to know whether in the future, a similar survey may attract much more attention if it was more easily able to be sent as a link to parents within health care trusts now that many health care trusts are interacting more electronically with parents and families.</p> <p>Supplementary files</p> <p>Do you need the ethics protocol within the supplementary files? This may be a requirement of BMJ Open?</p>
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VERSION 1 – AUTHOR RESPONSE

Dear Dr Singh and Professor Choonara,

Thank you for providing us with the opportunity to respond to the comments from yourselves and the two reviewers of our Manuscript ID bmjpo-2022-001425 entitled "Developing the FEEDS Toolkit of parent-delivered interventions for eating, drinking and swallowing difficulties in young children with neurodisability: Findings from a Delphi survey and stakeholder consultation workshops", submitted to BMJ Paediatrics Open. We hope that we have been able to address each of the points raised below and where appropriate in the revised manuscript. In responding to the reviewers comments the word count has increased slightly, this has been necessary to adequately address their comments.

Editor’s comments

1. Figure file format – Please note that we do not accept figures in Word document or PowerPoint format. All figures and images should be supplied as high quality image files, we recommend PNG, TIFF or JPG/JPEG. Please ensure images are a minimum of 300dpi and a maximum of 600dpi (resolution).
Response: Thank you for highlighting this, we have saved Figures 1 and 2 as JPEG files as requested to submit alongside the revised manuscript.

2. Abstract – Add number of parents and health professionals who participated

Response: Thank you for highlighting this, we have added the number of parents and health professionals who participated to the abstract as requested.

Reviewer 1

1. The only question I didn’t feel was fully addressed is the second question under the title ‘What this study adds?’ i.e. clarity of the interventions and outcomes to focus on within future research.

Response: Thank you to reviewer 1 for highlighting the opportunity for additional clarity within the paper with regards to the focus of future research. We have added the following additional text to address this “Rather than evaluating single standalone interventions, we suggest that future research should evaluate a combination of interventions within the FEEDS toolkit.”

Reviewer 2

1. Abstract - The abstract might benefit by describing the numbers of parents and health professionals sampled.

Response: Thank you to reviewer two for suggesting this, we have added the number of parents and health professionals who participated to the abstract as suggested.

2. Introduction – Should neurodisability be defined? And in relation to this, should there be any mention of whether children with ARFID are taken into account in this article or not – just to clarify – as it is something that many in the field are discussing presently.

Response: Thank you to reviewer 2 for their suggestion that neurodisability should be defined. We have added a definition of neurodisability and associated reference to the manuscript as follows “Long-term conditions affecting the brain, nerves and muscles are often grouped under the term ‘neurodisability’” and referenced the relevant article. With regards to whether children with ARFID are taken into account in this article, we have added some brief text to clarify this as follows (additional text underlined) “. Non-physical causes include rigidity or rituals associated with food or mealtimes, and sensory sensitivities to certain textures or flavours; this includes children with Avoidant / Restrictive Food Intake Disorder (ARFID).”

3. Methods – It may be worthwhile just reviewing an article which provides some guidelines on reporting on Delphi and consensus studies (Banno et al, 2019. Reporting Quality of the Delphi technique in reporting guidelines: a protocol for systematic analysis of the EQUATOR Network Library. BMJ Open. 2019; 9(4):e024942) and consider referencing this paper. Generally the guidelines are followed and it is clear how many participants took part in the survey and there is a clear criteria for dropping items as well as for defining consensus (>67%) with each stakeholder group needing to rate an intervention or outcome as essential (rated 7-9 at round 2). It is not clear whether there was any other “stopping criteria” rather than the rounds – a sentence on this might be worth adding. Could the authors explain why they chose >67%? The authors provide a little more information in this paper about exactly how the original survey was sent around and what kinds of parents tended to take part. This may be because it is referenced in other papers, however for this paper, it would be good to reiterate what the criteria for identifying participants was and whether this was reproducible and how participants were selected and excluded.

Response: Thank you to reviewer two for drawing attention to a paper outlining some guidelines on reporting on Delphi surveys, this was useful to read. Thank you also for their suggestions to provide further clarification around the Delphi survey methods. We chose to conservatively define consensus as $\geq 67\%$ to ensure that we were inclusive and that interventions that were useful for some children were not excluded during the rounds. There were no other stopping criteria used in the study. We aimed to do 2 to 3 rounds and were able to stop at two rounds as there was good agreement across the stakeholder groups. We have added in the following text about how participants were selected for the original survey “Participants were recruited through a wide range of sources, including NHS, professional and parent networks and schools. Full recruitment strategies are outlined elsewhere” and referenced the FEEDS published report.

4. Interventions chosen to go into Delphi: It is not entirely clear how the original interventions and ideas from parents were chosen to go into the Delphi – were they all included in the Delphi or only some and how was this chosen? The interventions provided are quite wide e.g. modifying environment or modifying position – was any more detail given at this stage to parents as to what types of interventions they could consider or come up with?

Response: We thank reviewer two for their request for clarity around how the original inventions were chosen to go into the Delphi survey. All interventions identified in the previous stages of the research (comprising three updated systematic reviews of interventions, a mapping review, a national survey and focus groups) were taken forward into the Delphi survey. In terms of clarifying what information was given to parents as to the types of interventions they could consider, at the focus groups we advised participants that we were interested in treatments or strategies for eating, drinking and swallowing difficulties for young children with neurodisability that could be delivered by parents at home. We asked participants which treatments or strategies they had experience of and what were the important outcomes to measure the success of treatments. Participants were advised that the terms “treatment” and “strategies” included what some people might call intervention, therapy, or advice.

5. Outcomes chosen to go into Delphi: How were outcomes in this survey prioritised? Were all outcomes previously identified prioritised?

Response: We thank reviewer two for their request for clarity as to how the outcomes were chosen to go into the Delphi survey. All outcomes identified in the previous stages of the research (comprising three updated systematic reviews of interventions, a mapping review, a national survey and focus groups)

were taken forward into the Delphi survey.

6. Were the 15 parents and 19 professionals all from the local surrounds? How were they chosen or did they choose themselves? Could you provide a little more demographic and specific information about this group – maybe specific diagnoses of children might add a bit and maybe age of parents and sociodemographics?.

Response: Thank you to reviewer two for asking for suggesting adding further information about the parents and professionals taking part in the workshops. The parents and professionals were local to the places where the workshops were being run or able to travel there within a reasonable cost. We have added the following text to clarify this: "Participants had to be able to travel to North East and South East England for the workshops." In relation to reviewer two's request for further demographic information on those who took part in the workshops, we did not systematically request additional demographic data to that already outlined in the manuscript and therefore this information is not available.

7. Procedure for group work: Were notes taken verbatim? How were they analysed thematically? Were there frameworks used? Were they done by hand? Were specific tools such as NVIVO used? Were the notes transcribed after into a computer? Who did the thematic analysis? How did the team decide on key themes? Who was the research team who decided this? A few additional details here might be helpful for the reader to understand the methodology and the rigour in the methodology at this stage.

Response: Thank you to reviewer two for suggesting adding further information about the procedure for analysing the information gathered from the workshops. Flip chart feedback compiled during the workshop discussions and the notes made at each group formed the data for the analysis. Two of the research team, with experience in qualitative research, reviewed all the data, identified key themes and presented the findings to the full research team for discussion. We have added in the following text (underlined) "Notes from the workshop discussions were reviewed by members of the research team and key themes identified; themes were then discussed by the full research team. For further details see Parr et al."

8. Table 4 – Some of the table looks like it was literally moved from a programme for analysis into a table and I wonder if the parts where it says "no missing data" should be removed?

Response: Thank you to reviewer two for their suggestion to remove the text referring to "no missing data" from the table. We assume the reviewer meant table 3 as there is no text referring to missing data in table 4. We have chosen to keep this information in the paper for transparency but have moved it to a footnote underneath table 3.

9. Limitations – One limitation that may be worth mentioning is that this study was done at a time before COVID where sending texts and electronically interacting with parents was harder. Most parents and professionals, as far as I can tell, were recruited by being provided a paper version of a leaflet with a link to a website. It would be interesting to know whether in the future, a similar survey may attract much more attention if it was more easily able to be sent as a link to parents within health care trusts now that many healthcare trusts are interacting more electronically with parents and families.

Response: We thank reviewer two for their suggestion around utilising online opportunities to engage with parents in the future now that this has become more commonplace and possibly including this as a limitation to the study. Multiple strategies were used to recruit parents to the study, including email, post, posters in clinic waiting areas and information leaflets. We did not offer online workshops, despite regularly using videoconferencing at the time of the study for other purposes, as we thought they would not be as effective as face-to-face workshops for the purposes of this study. For these reasons, we have not chosen to add this to the limitations of the study.

10. Supplementary files – Do you need the ethics protocol within the supplementary files? This may be a requirement of BMJ Open?

Response: Thank you to reviewer two for suggesting that the ethics protocol may need to be submitted as a supplementary file. We submitted the ethics protocol as a supplementary file alongside the original manuscript.

Kind regards

Dr Helen Taylor
Clinical Research Associate
On behalf of all authors