##

## FEEDS Report Supplementary Material File 1

## National survey questionnaire

The health professional’s version of the national survey is shown below.

The parent version differed from the health professional’s version in the following ways. It asked for additional information about the child being reported on: age; education setting; diagnosis; age EDSD started; whether there were continued EDSD; when EDSD resolved; cause of EDSD; involvement of health professionals; whether explanation / diagnosis given in relation to EDSD. It also asked the following questions in relation to each intervention: whether they had used it; what age their child was when they started using it; how long they used it for; which professionals recommended it; whether they thought it worked; whether they received training; and whether it was acceptable to deliver at home.

The education professional’s version differed from the health professional’s version in the following way. It asked whether respondents had been involved in delivering strategies aimed at improving EDSD. It also asked the following questions in relation to each intervention: whether they had been involved in using the strategy; whether they received training; whether they thought it worked; how long, on average, they thought it took to see changes; and whether it was acceptable to deliver in school.

**FEEDS Health Professionals Survey**

Please tell us some information about you:

|  |  |
| --- | --- |
| 1. What is your role? | Speech and Language Therapist Dietitian Occupational Therapist PhysiotherapistClinical Psychologist PaediatricianGastroenterologist NurseHealth VisitorOther (please specify)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| 2. How long have you been working with young people with neurodevelopmental disorders / neurodisability who experience eating, drinking or swallowing difficulties? | \_\_\_\_\_\_\_ years |
| 3. In which region of the UK do you work? | North East EnglandNorth West EnglandSouth East England including London South West EnglandMidlandsScotlandNorthern Ireland Wales |
| 4. Who is your employer? | NHS TrustIf so, which NHS Trust? (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_EducationVoluntary SectorIndependent PractitionerOther (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

Please tell us some information about your role with children who have eating, drinking and swallowing difficulties:

|  |  |
| --- | --- |
| 5. What age of children do you work with? (Please tick all that apply) | * 1. months

7-11 months1-3 years4-8 years9 years and above |
| 6. What type of eating, drinking and swallowing difficulties do you work with? | Physical difficulties*(Reduced control of the muscles of the lips, tongue, mouth and throat)*Non-physical difficulties*(Sensory sensitivity leading to restricted or selective eating and rituals associated with food or mealtimes)*Both physical and non-physical difficulties |
| 7. Which setting(s) do you work in? (Please tick all that apply) | Community Services Secondary CareTertiary Care EducationOther (please specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| 8. Which other professionals are involved with children’s eating, drinking and swallowing difficulties locally? | Speech and Language Therapist Dietitian Occupational Therapist PhysiotherapistClinical Psychologist PaediatricianGastroenterologist NurseHealth Visitor EducationOther (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| 9. Do you work with parents to deliver interventions? | Yes No  |
| 9a. IF NO, who supports parents to deliver interventions locally?(Please tick all that apply) | Speech and Language Therapist Dietitian Occupational Therapist PhysiotherapistClinical Psychologist PaediatricianGastroenterologist NurseHealth Visitor EducationOther (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Don’t know  |
| 10. Do you support education staff to deliver interventions? | Yes No  |
| 10a. IF NO, who supports education staff to deliver interventions locally?(Please tick all that apply) | Speech and Language Therapist Dietitian Occupational Therapist PhysiotherapistClinical Psychologist PaediatricianGastroenterologist NurseHealth Visitor Other (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Don’t know  |

In the next section we would like to know about the interventions you use with children with eating, drinking and swallowing difficulties. We appreciate that many interventions are used together as part of an overall treatment plan, but we are interested in knowing whether you use each of the component interventions listed (whether this is on its own or as part of a treatment plan). Some interventions are broad and some more specific. This study is about interventions parents can use at home and so we are not covering tube feeding (nasogastric or gastrostomy).

For each of the strategies listed in the tables following, please first answer whether you use or used it.

* If you answer ‘yes’ for that strategy, please go onto answer all the questions listed in the columns across the page in relation to that strategy.
* If you answer ‘no’ for that strategy, please go onto the next question below relating to the next strategy.

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents and school / nursery?****(tick Y/N for each)** |
| **11. Any type of positioning e.g. trunk stability, head movement, specialist seating** | Yes  No **If NO**, please move to question 12 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support   | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **12. Any type of manoeuvre e.g. jaw support, chin tuck** | Yes  No **If NO**, please move to question 13 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support   | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents and school / nursery?****(tick Y/N for each)** |
| **13. Any type of oral motor exercises to improve the child’s physical ability e.g. improving muscle tone, tongue strengthening** | Yes No **If NO**, please move to question 14 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Nursery: Yes  No  |
| **14. Any type of medication e.g. for epilepsy, pain, drooling, tone, gastro-oesophageal reflux** | Yes No **If NO**, please move to question 15 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Nursery: Yes  No  |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents or school / nursery?****(tick Y/N for each)** |
| **15. Schedule of meals to promote appetite or increase predictability e.g. written meal plan** | Yes  No **If NO**, please move to question 16 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **16. Any type of food or drink modification e.g. consistency, temperature, taste, volume** | Yes  No **If NO**, please move to question 17 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents or school / nursery?****(tick Y/N for each)** |
| **17.Any type of modification to eating and drinking utensils** | Yes  No **If NO**, please move to question 18 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoingsupport  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **18. Any type of modification to the environment at mealtimes e.g. noise, lighting, reduced social demands** | Yes  No **If NO**, please move to question 19 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoingsupport  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents or school / nursery?****(tick Y/N for each)** |
| **19. Any type of sensory aid e.g. glasses, hearing aids** | Yes  No **If NO**, please move to question 20 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **20. Use of energy supplements** | Yes  No **If NO**, please move to question 21 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents or school / nursery?****(tick Y/N for each)** |
| **21. Training to wait for child cues for feeding** | Yes  No **If NO**, please move to question 22 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **22. Pacing of food at mealtimes** | Yes  No **If NO**, please move to question 23 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents or school / nursery?****(tick Y/N for each)** |
| **23. Enhancing child / feeder communication strategies at mealtimes e.g. increasing choices** | Yes  No **If NO**, please move to question 24 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **24. Modifying social eating or drinking opportunities** | Yes  No **If NO**, please move to question 25 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents or school / nursery?****(tick Y/N for each)** |
| **25. Hand over hand prompting i.e. leading the child by the hand to teach skills such as self-feeding** | Yes  No **If NO**, please move to question 26 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **26. Counselling to parents / caregivers / staff of children with eating and drinking difficulties** | Yes  No **If NO**, please move to question 27 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents or school / nursery?****(tick Y/N for each)** |
| **27. Any type of desensitisation programme for food avoidance aimed at gradual acceptance of food e.g. messy play, sensory exploration, regular exposure to new foods** | Yes  No **If NO**, please move to question 28 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **28. Any type of graded desensitisation activity aimed at reducing a child’s excessive responses to oral sensations linked to eating and drinking e.g. face massage, chewing non foods** | Yes  No **If NO**, please move to question 29 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents or school / nursery?****(tick Y/N for each)** |
| **29. Any type of sensory stimulation e.g. tapping around mouth**  | Yes  No **If NO**, please move to question 30 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **30. Any type of sensori-motor therapy e.g. Facial Oral Tract Therapy** | Yes  No **If NO**, please move to question 31 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents or school / nursery?****(tick Y/N for each)** |
| **31. Being aware of the impact of movement difficulties on eating and drinking** | Yes  No **If NO**, please move to question 32 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **32. Being aware of the impact of sensory difficulties on eating and drinking** | Yes  No **If NO**, please move to question 33 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents or school / nursery?****(tick Y/N for each)** |
| **33. Any type of strategy or programme aimed at changing behaviour at mealtimes e.g. Positive Behaviour Support, reward charts** | Yes  No **If NO**, please move to question 34 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |
| **34. Any type of visual support e.g. visual timetable, ‘now and next’ board, ‘working towards’ board, sand-timers, social stories** | Yes  No **If NO**, please move to question 35 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Intervention for eating, drinking or swallowing difficulties** | **Do you use it?** | **What age range(s) do you use this with?****(tick all that apply)** | **Do you provide ongoing support with this intervention?****(tick one)** | **Which clinical group(s) do you use this with?****(tick one)** | **Where is it delivered?****(tick all that apply)** | **In your opinion, is it effective?****(tick one)** | **Over what timescale does change usually occur?****(tick one)** | **Is training given to parents or school / nursery?****(tick Y/N for each)** |
| **35. Any type of modelling e.g. learning to self-feed or to accept new foods, video modelling** | Yes  No **If NO**, please move to question 36 below | 0-6 months 7-11 months 1-3 years 4-8 years 9 years and above  | One-off intervention Time limited programme Ongoing support  | Physical difficulties Non-physical difficulties Both  | Home Nursery / playgroup School Hospital Other:\_\_\_\_\_\_\_\_\_\_\_\_ | Yes No Sometimes (please state when it is effective):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | 0-3 months 4-6 months 7-9 months 10-12 months Over 1 year  | Parents: Yes  No School / Yes Nursery: No  |

|  |  |
| --- | --- |
| 36. Are there other interventions **you use** that are not listed? | Yes No |
| 36a. If YES, please tell us what other interventions you use (Please list up to 3 interventions) | 1.\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_2.\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_3.\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| 37. Are there other interventions **you** **don’t currently use** but would like to recommend? | Yes No |
| 37a.If YES, please list up to 3 interventions you don’t use but would like to recommend | Intervention 1:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Why do you not use this now?\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_What appeals to you about this intervention?\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Intervention 2:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Why do you not use this now?\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_What appeals to you about this intervention?\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Intervention 3:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Why do you not use this now?\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_What appeals to you about this intervention?\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| 38. What do you think are the potential benefits of interventions for eating and drinking difficulties?(please tick all that apply) | Child physical health:Better general health (e.g. less colds or infections)Better sitting Fewer abnormal or unusual movements Fewer / shorter hospital admissionsImproved nutritionIncreased growthLess painWeight gainEating, drinking and swallowing performance:Better co-ordination of swallowing and breathingBetter oral-motor function (e.g. chewing, biting)Fewer breathing changes (rate, noise, effort, coughing, antibiotics courses, chest infections) linked to eating, drinking and swallowingLess aversion / avoidance of particular foodsLess drooling Less food / drink spilled from lips More food / drink consumedShorter mealtimesWider range of foods eatenChild’s quality of life and participation:Better mealtime one to one interaction with childBetter quality of life for childBetter self-feeding / independence skillsChild able to communicate better e.g. to express preferences or make choicesChild enjoys mealtimes moreChild less frustrated or distressed at mealtimesMore involvement in family’s activities e.g. eating with family or outside of the homeParent / carer / family related outcomes:Being able to eat a meal somewhere outside the homeBetter understanding of child’s difficulties and strategies to support themLess food waste / reduced cost of foodLess parental / carer stressMore opportunity to talk to others about feelings about child’s eating and drinking difficultiesNot having to prepare separate meals for the child Parent / carer / family enjoys mealtimes moreParent / carer / family less frustrated or distressed at mealtimesOther (please specify)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| 39. From the list above, which do you think are the **most important** outcomes for the child, parents and family? (please write 5 in the spaces provided) | * \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
 |
| 40. Do you measure eating and drinking outcomes? | Usually SometimesNever  |
| 40a-q. If YES:i) Which tools do you use to measure outcomesii) Which clinical groups do you use each tool with?(please tick all that apply) | **a. Brief Assessment of Motor Function - Oral Motor Deglutition Scale (BAMF-OMD):** i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**b. Behavioural Assessment Scale of Oral Functions in Feeding (BASOFF):** i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**c. Dysphagia Disorders Survey (DDS):**i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**d. Feeding Behaviour Scale (FBS):**i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**e. Functional Feeding Assessment (FFA):** i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**f. Gisel Video Assessment (GVA):** 1. Do you use this tool?

 Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**g. Oral Motor Assessment Scale (OMAS):** i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**h. Pre-Speech Assessment Scale (PSAS):** i ) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and**i. Schedule for Oral Motor Assessment (SOMA):** i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**j. Parenting Stress Index (PSI):** i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**k. Parental Stress Scale (PSS):** i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**l. Autism Parenting Stress Index (APSI):** i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**m. Parent Coping Scale (PCS):** i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**n. Questionnaire on Resources and Stress (QRS-F):**i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years **o. Vineland Adaptive Behaviour Scales (VABS):** i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**p. Family Impact Questionnaire (FIQ):** i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years**q. Therapy Outcome Measures (TOMS):** i) Do you use this tool?  Yes  No ii) If YES, which clinical groups do you use it with? Physical disabilities Non-physical disabilities 8 years and under Over 8 years |
| 41. Do **you use** any other outcome measures not listed above? | Yes No |
| 41a. If YES, please:i) List up to 3 outcome measures you useii) State which clinical groups you use them with | 1. Name of tool:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Physical disabilities Non-physical disabilities 8 years and under Over 8 years2. Name of tool:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Physical disabilities Non-physical disabilities 8 years and under Over 8 years3. Name of tool:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ Physical disabilities Non-physical disabilities 8 years and under Over 8 years |
| 42. Are there other measurement tools **you would like to use**? | Yes No  |
| 42a and b. If YES, please list up to 3 other tools you would like to use. | Measurement tools:1.\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_2.\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_3.\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Why do you not use them now?1.\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_2.\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_3.\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

**Please continue onto the next page.**

**This is the end of the first stage of the research. We hope that you will agree to also take part in the second stage of the research. This will involve completing another survey to help identify which interventions for eating, drinking and swallowing difficulties might be suitable for future research trials.**

43. Please tick if you would like to:

Go into a prize draw to win one of five £100 vouchers

Receive a summary of the survey results

Complete another survey in a few months

43a. If you have ticked a box above, please give your contact details so that we may contact you in the future:

Name:

Email address:

Postal address:

Thank you for taking part in this survey. We will summarise the results of the survey and the wider study in written summaries and on the FEEDS website: <http://research.ncl.ac.uk/neurodisability/ourstudies/feedsreview>

Please contact us if you have any questions using the contact details below:

Dr Helen Taylor

FEEDS study

Development & Disability Group, Newcastle University

3rd Floor, Sir James Spence Institute

Royal Victoria Infirmary

Queen Victoria Road

Newcastle upon Tyne

NE1 4LP

Tel: +44 (0)191 282 1379 Email: Feeds@ncl.ac.uk