## 

## 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:

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| 1. What is your role? | Speech and Language Therapist  Dietitian  Occupational Therapist  Physiotherapist  Clinical Psychologist  Paediatrician  Gastroenterologist  Nurse  Health Visitor  Other (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 England  North West England  South East England including London  South West England  Midlands  Scotland  Northern Ireland  Wales | |
| 4. Who is your employer? | NHS Trust  If so, which NHS Trust? (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Education  Voluntary Sector  Independent Practitioner  Other (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ | |

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

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| 5. What age of children do you work with?  (Please tick all that apply) | * 1. months   7-11 months  1-3 years  4-8 years  9 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 Care  Tertiary Care  Education  Other (please specify) \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
| 8. Which other professionals are involved with children’s eating, drinking and swallowing difficulties locally? | Speech and Language Therapist  Dietitian  Occupational Therapist  Physiotherapist  Clinical Psychologist  Paediatrician  Gastroenterologist  Nurse  Health Visitor  Education  Other (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  Physiotherapist  Clinical Psychologist  Paediatrician  Gastroenterologist  Nurse  Health Visitor  Education  Other (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  Physiotherapist  Clinical Psychologist  Paediatrician  Gastroenterologist  Nurse  Health 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.

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| **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 |

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| **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 |

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| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **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 |

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| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **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  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 |
| **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  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 |

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| **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 |

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| **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 |

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| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **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 |

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| **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 |

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| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **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 |

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| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **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) ||
| 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 admissions  Improved nutrition  Increased growth  Less pain  Weight gain  Eating, drinking and swallowing performance:  Better co-ordination of swallowing and breathing  Better oral-motor function (e.g. chewing, biting)  Fewer breathing changes (rate, noise, effort, coughing, antibiotics courses, chest infections) linked to eating, drinking and swallowing  Less aversion / avoidance of particular foods  Less drooling  Less food / drink spilled from lips  More food / drink consumed  Shorter mealtimes  Wider range of foods eaten  Child’s quality of life and participation:  Better mealtime one to one interaction with child  Better quality of life for child  Better self-feeding / independence skills  Child able to communicate better e.g. to express preferences or make choices  Child enjoys mealtimes more  Child less frustrated or distressed at mealtimes  More involvement in family’s activities e.g. eating with family or outside of the home  Parent / carer / family related outcomes:  Being able to eat a meal somewhere outside the home  Better understanding of child’s difficulties and strategies to support them  Less food waste / reduced cost of food  Less parental / carer stress  More opportunity to talk to others about feelings about child’s eating and drinking difficulties  Not having to prepare separate meals for the child  Parent / carer / family enjoys mealtimes more  Parent / carer / family less frustrated or distressed at mealtimes  Other (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  Sometimes  Never |
| 40a-q. If YES:  i) Which tools do you use to measure outcomes  ii) 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 use  ii) State which clinical groups you use them with | 1. Name of tool:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Physical disabilities Non-physical disabilities  8 years and under Over 8 years  2. Name of tool:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_  Physical disabilities Non-physical disabilities  8 years and under Over 8 years  3. 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 toolshy do you not use them now|

**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:

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