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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

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ABSTRACT

Background

Young children with neurodisability commonly experience eating, drinking and swallowing difficulties (EDSD). Little is documented about which interventions and outcomes are most appropriate for such children. We aimed to seek consensus between parents of children with neurodisability and health professionals on the appropriate interventions and outcomes to inform future clinical developments and research studies.

Methods

Two populations were sampled: parents of children aged up to 12 years with neurodisability who experienced EDSD; health professionals working with children and young people (aged 0-18 years) with neurodisability with experience of EDSD. Participants had taken part in a previous national survey and were invited to take part in a Delphi survey and / or consultation workshops. Two rounds of this Delphi survey sought agreement on the appropriate interventions and outcomes for use with children with neurodisability and EDSD. Two stakeholder consultation workshops were iterative, with the findings of the first discussed at the second, and conclusions reached.

Results

Parents and health professionals viewed 19 interventions and 10 outcomes as essential. Interventions related to improvement in the physical aspects of a child's EDSD, behavioural changes of the child or parent, and changes in the child or family's well-being. Both parents and health professionals supported a 'toolkit' of interventions that they could use together in shared decision making to prioritise and implement timely interventions appropriate to the child.

Conclusions

This study identified interventions viewed as essential to consider for improving EDSD in children with neurodisability. It also identified several key outcomes that are valued by parents and health professionals. The FEEDS Toolkit of

interventions to improve EDSD in children with neurodisability has been developed and now requires evaluation regarding its use and effectiveness.

What is known about the subject?

- Children with neurodisability commonly experience eating, drinking and swallowing difficulties (EDSD) that have physical and non-physical causes.
- EDSD have a considerable impact on a child and family.
- A UK survey found a wide range of parent-delivered interventions are recommended by health professionals and used by parents to support young children with neurodisability.

What this study adds?

- Agreement from parents and health professionals on the appropriate interventions and outcomes for use with children with neurodisability and EDSD.
- Clarity on the interventions and outcomes to focus on within future research
- A toolkit of interventions was developed for use by health professionals and parents to support children with neurodisability and EDSD.

INTRODUCTION

Children with neurodisability commonly experience eating, drinking and swallowing difficulties (EDSD) that have physical and non-physical causes. Physical causes relate to decreased muscle control and co-ordination, which impairs the safety and efficiency of sucking, chewing and swallowing. Non-physical causes include rigidity or rituals associated with food or mealtimes, and sensory sensitivities to certain textures or flavours. Physical and non-physical EDSD frequently co-exist (mixed EDSD). EDSD make mealtimes stressful for children and their families and impact negatively on quality of life and social participation. They also lead to inadequate calorie intake or a restricted diet, affecting a child's nutrition, growth and physical health (1).

A recent UK survey of parents and health professionals found a wide range of interventions were used for children with neurodisability who experience EDSD to address their physiological and behavioural needs (2). The survey found most children received multiple interventions. There was a common approach to addressing EDSD regardless of the cause of the child's difficulties, with the majority of interventions being used to address all types of EDSD. This survey also identified a range of important outcomes to measure the effectiveness of interventions.

As part of a larger research programme, FEEDS (Focus on Early Eating, Drinking and Swallowing) (3), this study aimed to:

1. Seek consensus between parents and health professionals on which interventions and outcomes are most appropriate for children with neurodisability and EDSD.

2. Gain consensus between parents and health professionals on which interventions should be evaluated in future research.

3. Develop a 'toolkit' of interventions that could be used by health professionals and parents to support children with EDSD and their families.

METHODS

An iterative online Delphi survey and two stakeholder consultation workshops were undertaken.

Delphi survey

Participants

Invitations to participate were sent to respondents from the FEEDS national survey (2) who had expressed interest in subsequent research stages. This included: parents of children (aged up to 12 years) with neurodisability who experienced EDSD; and health professionals working with children and young people (aged 0-18 years) with neurodisability.

Measure

The questionnaire listed interventions and outcomes identified in earlier stages of the FEEDS research programme (3). The questionnaire's structure and format was developed with reference to methodological recommendations (4) and previous experience of Delphi surveys. The questionnaire contained three sections [1] demographic characteristics; [2] parent-delivered interventions for young children with neurodisability and EDSD; and [3] outcomes to measure improvement in EDSD.

Questions related to 25 interventions and 22 outcomes (Tables 1 and 2). Respondents rated the importance of the interventions as part of a treatment package for EDSD, and the outcomes to measure (using a 9-point scale: 0-3 'not important', 4-6 'important but not essential', 7-9 'essential'). Respondents could tick "unable to score". The questionnaire was hosted on Qualtrics (5).

Table 1. Description of interventions presented in Delphi Survey

Intervention	Description
Modifying environment	Changing the physical or social setting at mealtimes (e.g. reducing distractions such as levels of noise; using distractions to reduce a child's attention on their food
Positioning	Ensuring a child is in the best position to eat and drink food safely and efficiently (e.g. a child sitting upright providing support for head control)
Modifying equipment	Using different spoons, forks, plates, cups, or bottles (e.g. doidy cup; plastic spoon)
Scheduling of meals	Setting the timing of mealtimes to encourage a child's appetite and establish a mealtime routine (e.g. spreading meals / snacks throughout the day; setting a 30 minutes limit for mealtimes)
Modifying consistency of food	Changing the consistency of the child's food or drink (e.g. pureeing food; thickening food or drink)
Modifying other aspects of food	Changing the temperature, taste, amount or presentation of the child's food or drink (e.g. presenting different foods so they do not touch each other; mixing liked foods with disliked foods)
Modifying placement of food	Changing where food is placed in a child's mouth to help chewing or swallowing (e.g. placing food to the side of the mouth)
Enhancing communication	Improving communication between a child and the person feeding them during mealtimes (e.g. offering choices of food to a child; a child using eye pointing or signs or symbols to ask for specific food or drink)
Visual supports	Use of pictures, a 'countdown clock', or social stories to increase a child's understanding of what happens during mealtimes (e.g. showing a child pictures of what

	food will be on their plate; showing a child a story to explain what will happen during a mealtime)
Responding to a child's cues for feeding	Helping people to recognise the signs that a child is ready to take another mouthful of food or drink (e.g. looking for breath alterations or repeated swallows from a child to indicate a lack of readiness)
Pace of feeding	Changing the speed at which each mouthful of food or drink is taken by a child (e.g. slowing pace down to prevent overfilling of a child's mouth)
Medication	Any medication (e.g. for epilepsy, pain, drooling, tone, gastroesophageal reflux)
Energy supplements	Any energy or calorie supplement given orally or via feeding tube
Vitamin or nutritional supplements	Any supplements given or changes to a child's diet to increase the vitamins or nutrients in their diet
Physical support	Giving direct physical support to a child when eating or drinking to improve the movements needed to bite, chew and swallow (e.g. placing a thumb underneath the chin to help a child close their mouth)
Oral and sensory desensitisation	Activities aimed at reducing a child's adverse reactions to different sensory experiences linked to eating and drinking (e.g. face massage; chewing no-food items such as a chewy 'toothbrush')
Oral-motor exercises	Exercises done with a child to improve the control of their mouth, jaw, tongue or lips (e.g. a child moving a non-food item with their tongue; a child sucking through a straw)
Graded exposure to new food	Activities aimed at gradually exposing a child to new or disliked foods and drinks (e.g. messy play activities involving a child touching new or disliked foods; using small steps towards a child accepting new or disliked foods such as licking the food or putting it in their mouth with no expectation to swallow)

Graded exposure to new textures	Activities aimed at gradually introducing a child to more challenging food textures and fluid consistencies (e.g. messy play activities involving a child touching new or disliked textures; using small steps to introduce a child to lumpy food or foods that require chewing)
Changing behaviour at mealtimes	Strategies to encourage a child to behave appropriately at mealtimes (e.g. a child sitting down ready to eat; a child staying seated for the meal)
Modelling	Giving a child the opportunity to learn from others by eating and drinking with them (e.g. sitting a child with other children or family members at mealtimes)
Training to self-feed	Teaching a child to feed themselves (e.g. placing a hand over a child's hand to help guide the food into their mouth)
Support for parents	Help for parents around their child's eating and drinking difficulties (e.g. counselling; parent support groups)
Sharing information	Any information shared to help parents and professional understand a child's difficulties with eating and drinking (e.g. professionals teaching parents and school staff about a child's physical or sensory difficulties; parents helping professionals understand what's important about mealtimes in their family)
Psychological support for children	Psychological help for a child (e.g. counselling)

Table 2. Description of outcomes presented in Delphi Survey

Outcome	Description
General health	A child's overall health
Weight	How much a child weighs
Height	How tall a child is
Growth	A change in a child's growth, including height and weight
Nutrition	A child's level of energy and nutrients for healthy growth
Child's enjoyment of mealtimes	
Parent or caregiver's enjoyment of mealtimes	
Quality of life of child	How satisfied a child feels about their life
Quality of life of family	How satisfied other family members feel about their (own) lives
Mental health of parent or caregiver	A parent / caregiver's mood and emotional wellbeing
Safety	A child's ability to eat and drink safely without choking or aspirating
Oral motor control	A child's ability to control the movement of their mouth, jaw, tongue or lips and swallow
Efficiency	A child's ability to eat and drink at a reasonable pace
Independence	A child's ability to feed themselves
Variety	The range of foods or liquids a child eats or drinks
Amount	The amount of food or liquid a child eats or drinks per day
Appetite	A child's level of hunger and desire for food / drink
Mealtime behaviour	A child behaving appropriately during meals
Mealtime interaction	The interaction between a child and the person feeding them at mealtimes
Social participation	A child's overall involvement at mealtimes

Child’s understanding	A child’s understanding of mealtime activities and routines
Parent or caregiver’s understanding	A parent / caregiver’s insight into their child’s eating and drinking difficulties

Patient and public involvement

The questionnaire and information sheet were developed by the research team, which included parent co-investigators, in consultation with the Parent Advisory Group (PAG) and following focus groups with parents and health professionals (3).

Procedure

The same questionnaire was sent to parents and health professionals in two rounds. In round one, respondents rated the importance of individual intervention categories, and outcomes. In round two, respondents were shown bar charts of parent and health professionals' ratings from round one and then re-rated the importance of each intervention and outcome. No items were removed between rounds. Both survey rounds were open for three weeks with a week between rounds for data analysis (March-May 2019). Respondents and non-respondents from round one were invited to take part in round two, to maximise participation. Round two respondents entered a prize draw to win one of five £100 vouchers for each stakeholder group.

Analysis

Consensus was conservatively defined as ≥ 67% and required each stakeholder group to rate an intervention or outcome as essential (rated 7-9 at round two) (4).

Stakeholder workshops

Participants

Parents who took part in the FEEDS national survey (2) and had expressed interest in subsequent research stages were invited to participate. Invitations were sent to health professionals linked to regional and national clinical networks.

Participants were purposively selected to maximise variation in their experience of EDSD and service provision.

Design

Two half-day workshops were held (Newcastle upon Tyne and London) in May 2019. The workshops aimed to facilitate detailed discussion on [1] Which interventions and outcomes should be evaluated in future research?; [2] A proposed intervention 'toolkit' for EDSD (developed during previous study stages), including: How could the essential interventions identified in the Delphi survey be presented to parents as a list of treatment options?; What level of detail would parents need on each intervention?; How would a menu of treatment options be individualised?; What level of support would families need from health professionals to use the toolkit?

Patient and public involvement

Parent co-investigators were involved in the design and delivery of the workshops. The PAG also reviewed workshop materials and commented on the structure and timings of tasks.

Procedure

Attendees were presented with a study overview including the main findings from earlier research stages. Individual topics were discussed in small mixed groups of parents and professionals. One research team member facilitated each group and notes were taken. The workshops were iterative, with the results of the first workshop being presented at the second. To thank them for their time and/or cover travel costs, parents and professionals received a shopping voucher.

Notes from the workshop discussions were reviewed and key themes identified; themes were then discussed by the research team.

RESULTS

Delphi survey

196 parents and 175 health professionals were invited (see Figure 1). 81 parents (41%) and 61 parents (31%) responded to rounds one and two respectively, with 52 parents responding to both rounds. 76 health professionals (43%) and 61 health professionals (35%) responded to rounds one and two respectively, with 51 health professionals responding to both rounds.

[Insert figure 1 about here]

Participant Characteristics

The characteristics of respondents are shown in Table 3. Similar proportions of parents and health professionals participated in round one (49% and 51% respectively), and round two (50% and 50% respectively). The characteristics of respondents who completed both rounds and those who completed round two only were very similar. See Supplementary Tables 1 and 2 for full details of respondents and non-respondents.

Table 3. Characteristics of Delphi Survey respondents for Rounds 1 and 2

	Round 1 N=158		Round 2 N=123	
	Parents N=81 n (%)	HPs N=76 n (%)	Parents N=61 n (%)	HPs N=61 n (%)
Age (no missing data)				
Under 20 years	0 (0)	0 (0)	0 (0)	0 (0)
21-30 years	2 (3)	8 (11)	2 (3)	3 (5)
31-40 years	32 (40)	19 (25)	23 (38)	17 (28)
41-50 years	40 (49)	25 (33)	32 (53)	20 (33)
51-60 years	7 (9)	22 (29)	4 (7)	20 (33)
61 years and over	0 (0)	2 (3)	0 (0)	1 (2)
Gender (no missing data)				

Female	76 (94)	71 (93)	58 (95)	58 (95)
Male	5 (6)	4 (5)	3 (5)	3 (5)
Prefer not to say	0 (0)	1 (1)	0 (0)	0 (0)
Location				
England				
North East	14 (17)	5 (7)	11 (18)	7 (12)
North West	8 (10)	3 (4)	6 (10)	3 (5)
Yorkshire and Humber	5 (6)	10 (13)	2 (3)	9 (15)
Midlands	11 (14)	16 (21)	9 (14)	10 (16)
South East including London	27 (33)	26 (34)	20 (33)	21 (34)
South West	8 (10)	8 (11)	7 (12)	4 (7)
Scotland	3 (4)	4 (5)	2 (3)	5 (8)
Northern Ireland	2 (3)	0 (0)	2 (3)	0 (0)
Wales	1 (1)	4 (5)	1 (2)	2 (3)
Missing	2 (3)	0 (0)	1 (2)	0 (0)
Ethnicity (no missing data)				
White	78 (96)	70 (92)	59 (97)	55 (90)
Asian / Asian British	2 (3)	3 (4)	0 (0)	4 (7)
Black / African / Caribbean / Black British	0 (0)	0 (0)	1 (2)	0 (0)
Mixed / Multiple ethnic group	1 (1)	1 (1)	1 (2)	1 (2)
Other ethnic group	0 (0)	2 (3)	0 (0)	1 (2)
Prefer not to say	0 (0)	0 (0)	0 (0)	0 (0)
Nature of child's EDSD				
Physical EDSD	14 (17)	14 (18)	9 (15)	13 (21)
Nonphysical EDSD	40 (49)	5 (7)	32 (53)	3 (5)
Mixed EDSD	27 (33)	57 (75)	20 (33)	45 (74)
Missing	0 (0)	0 (0)	0 (0)	0 (0)

Interventions for children with neurodisability and EDSD

Table 4 shows the proportion of parents and health professionals who rated interventions as essential in rounds one and two. Consensus was achieved for 17/25 interventions at round one, increasing to 19/25 interventions at round two. The interventions rated as an essential part of an intervention package for young children with neurodisability and EDSD are shown in Table 4. See Supplementary Tables 3 and 4 for all intervention ratings.

Table 4. Parents' and health professionals' rating of interventions as essential on Round 1 and 2 of the Delphi Survey

Bold denotes a rating of 'essential' (score 7-9) by ≥ 67% within the stakeholder group. Shaded cell denotes agreement by both stakeholder groups that the item was 'essential' (score 7-9) ≥ 67%.

	Round 1	Round 2

Intervention	Parents N = 81 %	Health professionals N = 76 %	Parents N = 61 %	Health professionals N = 61 %
Modifying environment	**67**	**87**	**77**	**95**
Positioning	**92**	**97**	**96**	**100**
Modifying equipment	**76**	**87**	**93**	**90**
Scheduling of meals	53	**82**	50	**83**
Modifying consistency of food or drink	**79**	**86**	**79**	**96**
Modifying other aspects of food or drink	**74**	**75**	**86**	**83**
Modifying placement of food	**68**	**79**	**75**	**90**
Enhancing communication	**76**	**82**	**86**	**90**
Visual supports	52	63	52	**72**
Responding to a child's cues for feeding	**83**	**94**	**93**	**96**
Pace of feeding	**77**	**96**	**89**	**100**
Physical support	**72**	**69**	**82**	**81**
Oral and sensory desensitisation	**72**	**68**	**82**	**75**
Oral-motor exercises	**73**	40	**70**	35
Graded exposure to new food	66	**85**	**70**	**84**
Graded exposure to new textures	**68**	**81**	**76**	**81**
Changing behaviour at mealtimes	57	63	58	56
Modelling	**80**	**82**	**77**	**83**
Training to self-feed	**68**	47	55	46
Support for parents	**81**	**84**	**95**	**96**
Psychological support for child	**72**	63	**77**	59
Medication	**78**	**86**	**87**	**91**
Energy supplements	62	**74**	**69**	**73**
Sharing information	**90**	**95**	**100**	**97**
Vitamin or nutritional supplements	**68**	**68**	**85**	**75**

Outcomes for children with neurodisability and EDSD

Table 5 shows the proportions of parents and health professionals who rated outcomes as essential in rounds one and two. The outcomes for which there was consensus on did not change between rounds. 10 outcomes were viewed as essential; some related to physical health, such as safety and growth, and others to the International Classification of Functioning Disability and Health, such as child social participation. See Supplementary Tables 5 and 6 for all outcome ratings.

Table 5. Parents' and health professionals' agreement on outcomes rated as essential on Round 1 and Round 2 of the Delphi Survey

Bold denotes a rating of ‘essential’ (score 7-9) by ≥ 67% within the stakeholder group. Shaded cell denotes agreement by both stakeholder groups that the item was ‘essential’ (score 7-9) ≥ 67%.

Outcome	Round 1		Round 2	
	Parents N = 81	Health professionals N=76	Parents N=61	Health professionals N=61
Nutrition	**89**	**97**	**95**	**98**
General Health	**89**	**93**	**97**	**98**
Weight	53	51	34	48
Height	31	32	12	12
Growth	**75**	**76**	**82**	**89**
Child’s enjoyment of mealtimes	**83**	**91**	**90**	**98**
Parent’s enjoyment of mealtimes	42	**76**	39	**78**
Quality of life of child	**95**	**92**	**98**	**100**
Quality of life of family	**78**	**87**	**90**	**97**
Mental health of parent	**83**	**84**	**93**	**97**
Safety	**97**	**97**	**100**	**100**
Oral-motor control	**87**	**74**	**86**	**72**
Efficiency	44	60	17	46
Independence	60	31	43	28
Variety	51	23	26	12
Amount	62	40	53	25
Appetite	59	44	46	38
Mealtime behaviour	41	30	34	26
Mealtime Interaction	61	**81**	65	**79**
Social participation	50	**77**	53	**74**
Parent’s understanding of child’s EDSD	**89**	**89**	**95**	**93**
Child’s understanding of mealtimes	51	51	58	40

Stakeholder Workshops

15 parents and 19 health professionals took part in the workshops.

Participant Characteristics

Nine parents had children with physical EDSD, two had children with non-physical EDSD, two had children with mixed EDSD, and two had one child with physical EDSD and one child with non-physical EDSD. Health professionals comprised six speech and language therapists, four dietitians, four paediatricians, three occupational therapists, two clinical psychologists, a physiotherapist, and a nurse.

Interventions and outcomes for evaluation in future research

Parents and health professionals agreed that no single intervention was suitable for all children with EDSD as many children require a number of interventions concurrently or sequentially. Both parents and health professionals endorsed the idea of an intervention ‘toolkit’ that could be used together to identify the most appropriate interventions for individual children and their families. They thought the toolkit should be visually represented and be available as a digital and hard copy with interactive properties to support communication between parents and professionals. They emphasised the need for flexibility in the toolkit to allow families and health professionals to select the most appropriate interventions, at the right time. Some parents thought they would want to be able to see the whole toolkit, to facilitate a central parental role in intervention prioritisation. Parents and health professionals thought that detailed information was needed for each intervention to fully inform families and allow them to share in decision-making.

Paricipants thought a lead health professional (such as a speech and language therapist) and multidisciplinary team should support families in their toolkit use. The nature of support needed would vary between families and may include psychological input. Parents and health professionals raised a number of practical issues about toolkit use, including: how to deliver the toolkit to meet the needs of a heterogeneous population with diverse EDSD; how to deliver the toolkit where multidisciplinary EDSD team professionals are unavailable or under-resourced; and how to deliver the toolkit to children with non-physical EDSD who may not currently receive multidisciplinary team healthcare.

Toolkit of interventions for children with neurodisability and EDSD

Using the findings from the Delphi survey and workshops, alongside findings from other stages of the FEEDS research programme (3), we developed the FEEDS Toolkit of interventions for use by health professionals and parents to support children with neurodisability and EDSD (see Figure 2). The FEEDS Toolkit comprises 19 EDSD interventions: 15 for use with children with all types of EDSD, two for use with children with physical or mixed EDSD only and two that are rarely offered by the UK NHS (oral motor excercises and psychological support for the child). The FEEDS Toolkit also includes ongoing interventions that influence EDSD strategies such as individual context, medical issues and sharing information.

[Insert figure 2 about here]

DISCUSSION

The Delphi survey established consensus on the 19 essential interventions to include in the FEEDS Toolkit, and 10 outcomes of importance. The stakeholder workshops showed support from parents and health professionals for the FEEDS Toolkit that could be worked through by health professionals and parents.

The large number and diversity of interventions identified as essential for inclusion in the toolkit reflects the heterogeneity of children with neurodisability and EDSD, and their families. Beresford et al (6) found health professionals working with children with neurodisability had a “great big menu of interventions to choose from” which were highly individualised. Health professionals talked about taking an eclectic approach and using a range of interventions from their toolbox with children with neurodisability and their families; key factors affecting decision making regarding appropriate interventions included child and family’s characteristics and resources (6). McAnuff et al (7) described a prototype for an interactive toolkit to support families and health professionals to identify opportunities for change, and to jointly select appropriate interventions. This is in keeping with views regarding how the FEEDS toolkit might be operationalised.

[illegible]

Strengths and limitations

We acknowledge the potential risks of sampling and response bias. Participants from the FEEDS national survey were recruited from wide ranging sources (3); their data allowed comparison of the characteristics of Delphi survey respondents and non-respondents. The overall response (≈40%) was acceptable. There was minimal difference between the characteristics of respondents between rounds one and two Through contacting non-respondents from round one in round two we increased round two responses thereby improving precision. We used a conservative consensus definition of ≥67%; our findings may have differed if we had used different consensus definitions.

The workshops had representation from two diverse geographical areas and parents and professionals with a broad range of EDSD experiences. The iterative nature of the workshops facilitated detailed discussions. Young people with EDSD were not invited to the workshops; however, at separate young people's focus groups, they agreed the importance of the outcomes identified (3).

Conclusions

The FEEDS Delphi survey and workshops identified the interventions essential to consider for improving EDSD in children with neurodisability. They also identified the most important outcomes to measure, focusing on both the child and the wider family. These findings, alongside findings from earlier stages of the FEEDS research programme (3) have been used to develop a toolkit of interventions. The FEEDS Toolkit requires evaluation of its feasibility and acceptability, and its effectiveness for improving outcomes for children and families.

Contributors: JP was Chief Investigator, co-led the design and delivery of the study, supervised the Delphi survey data analysis, co-led the consultation workshops and

analysed the data. LP co-led the design and delivery of the project, co-led the consultation workshops and analysed the data. HT developed the Delphi survey materials, ran the Delphi survey and analysed the data, and co-led the consultation workshops. CM, JC, DS, JS, DG, JT and EM contributed to the design of the Delphi survey. CB, AC, DG, CM, HM, JS, JT, JC and DS co-facilitated the consultation workshops. All authors contributed to the study design, interpretation of results, writing of the manuscript, and reviewed and approved the final version.

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The NIHR HTA report from the research (including that reported in this manuscript) can be found at: https://www.journalslibrary.nihr.ac.uk/hta/hta25220/#/full-report

Competing interests: Diane Sellers received a research grant from Nutricia Advanced Medical Nutrition UK (Wiltshire, UK) from 2017 to 2018, honorarium payments from Nutricia Advanced Medical Nutrition UK from 2015 to 2019 and an honorarium payment from Nutricia Advanced Medical Nutrition UK in 2018. Morag Andrew received fees from Nutricia Advanced Medical Nutrition UK to attend a conference in which she was presenting industry partner research work and lecture fees/symposium presentation fees from Nutricia Advanced Medical Nutrition UK and Nestlé SA (Vevey, Switzerland). Jill Cadwgan reports personal fees from Novartis Pharmaceuticals (Basel, Switzerland) and Allergan, and Ispen Pharmaceuticals (Paris, France).

Patient consent for publication: Not required

Ethics approval: This study was approved by The West Midlands and the Black Country Research Ethics Committee (17/WM/0439). Completion of the Delphi survey was taken as informed consent and informed consent was taken at the start of the stakeholder workshops.

Data availability statement: Data that support the findings of this study are available on request from the corresponding author [JP].

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Figure 1. Flow diagram of Delphi Survey recruitment

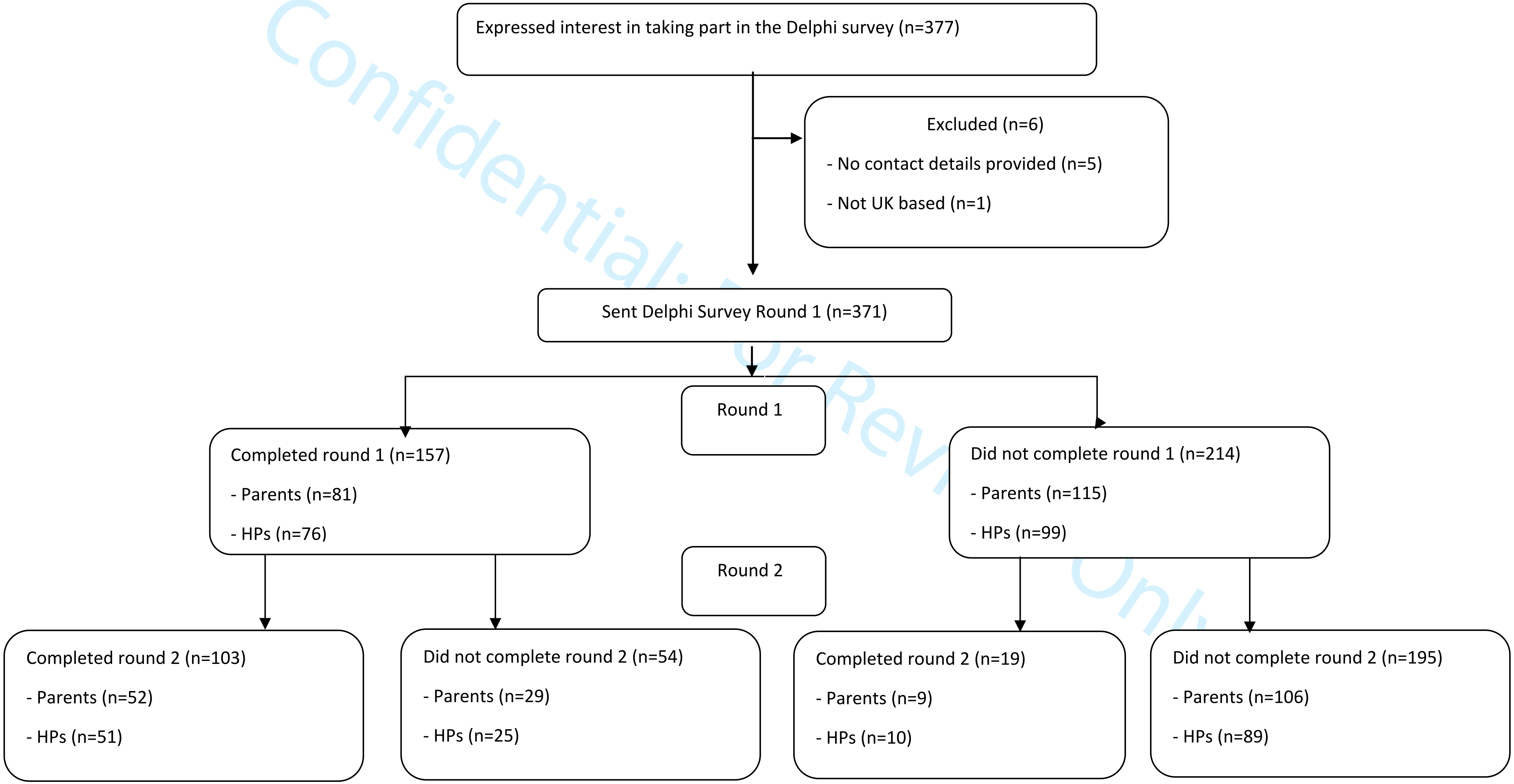
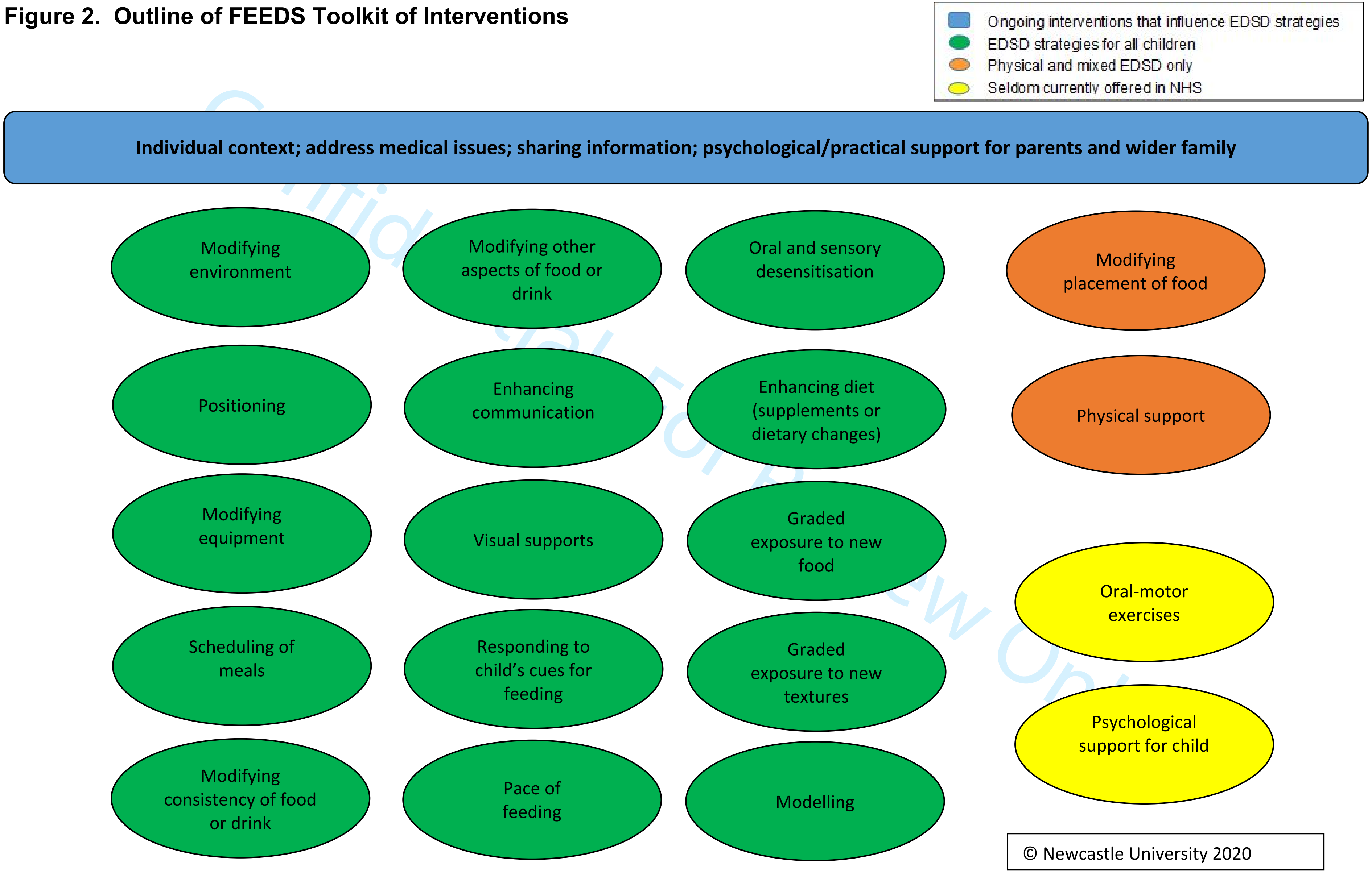


Figure 2. Outline of FEEDS Toolkit of Interventions



Supplementary Table 1. Characteristics of respondents who completed both rounds of Delphi Survey and those who only completed Round 2

	Round 1 and 2 N=103	**Round 2 only N=19**
Role		
Parent	52 (51) [c]	9 (47)
Health Professional	51 (50) [c]	10 (53)
Age		
Under 20 years	0 (0)	0 (0)
21-30 years	5 (5)	0 (0)
31-40 years	28 (27)	12 (63)
41-50 years	47 (46)	5 (26)
51-60 years	22 (21)	2 (11)
61-70 years	0 (0)	0 (0)
Over 70 years	1 (1)	0 (0)
Missing	0 (0)	0 (0)
Gender		
Female	98 (95)	18 (95)
Male	5 (5)	1 (5)
Prefer not to say	0 (0)	0 (0)
Missing	0 (0)	0 (0)
Location		
England		
North East	15 (15)	3 (16)
North West	8 (8)	1 (5)
Yorkshire and Humber	9 (9)	2 (11)
Midlands	15 (15)	4 (21)
South East including London	35 (34)	6 (32)
South West England	10 (10)	1 (5)
Scotland	5 (5)	2 (11)
Northern Ireland	2 (2)	0 (0)
Wales	3 (3)	0 (0)
Missing	1 (1)	0 (0)
Ethnicity		
White	98 (95)	16 (84)
Black / African / Caribbean / Black British	0 (0)	1 (5)
Asian / Asian British	3 (3)	1 (5)
Mixed / Multiple ethnic group	2 (2)	0 (0)
Other ethnic group	0 (0)	1 (5)
Prefer not to say	0 (0)	0 (0)
Missing	0 (0)	0 (0)
Type of EDSD of child[a]		
Physical EDSD	21 (20)	1 (5)
Non-physical EDSD	28 (27)	7 (37)
Mixed EDSD [b]	54 (52)	11 (58)
Missing	0 (0)	0 (0)

[a] EDSD refers to eating, drinking and swallowing difficulties. [b] Mixed EDSD refers to children with physical and non-physical causes to their EDSD. [c] Percentages add up to more than 100% as a result of rounding the number to the nearest whole number.

Supplementary Table 2. Characteristics of non-respondents to the Delphi Survey

	Non-respondents N=195	
	Parents N=269 n (%)	HPs N=335 n (%)
Age (no missing data)		
Under 20 years	5 (2)	- [a]
21-30 years	23 (9)	- [a]
31-40 years	130 (48)	- [a]
41-50 years	95 (35)	- [a]
51-60 years	14 (5)	- [a]
61 years and over	2 (1)	- [a]
Gender (no missing data)		
Female	254 (94)	- [a]
Male	15 (6)	- [a]
Prefer not to say	0 (0)	- [a]
Location		
England		
North East	48 (18)	29 (9)
North West	20 (7)	22 (7)
Yorkshire and Humber	28 (10)	49 (15)
Midlands	66 (25)	47 (14)
South East including London	56 (21)	136 (41)
South West	29 (11)	14 (4)
Scotland	11 (4)	14 (4)
Northern Ireland	4 (2)	11 (3)
Wales	7 (3)	13 (4)
Missing	0 (0)	0 (0)
Ethnicity (no missing data)		
White	234 (87)	- [a]
Asian / Asian British	22 (8)	- [a]
Black / African / Caribbean / Black British	4 (2)	- [a]
Mixed / Multiple ethnic group	7 (3)	- [a]
Other ethnic group	0 (0)	- [a]
Prefer not to say	2 (1)	- [a]
Nature of child's EDSD		
Physical EDSD	58 (22)	63 (19)
Nonphysical EDSD	141 (52)	23 (7)
Mixed EDSD	59 (22)	248 (74)
Missing	11 (4)	0 (0)

[a] Data not collected in national survey.

Supplementary Table 3. Parents' and health professionals' ratings of interventions on Round 1 of the Delphi Survey

	n	Not Important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %	n	Not important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %
Modifying environment	78	3	31	**67**	74	0	14	**87**
Positioning	72	1	7	**92**	74	0	3	**97**
Modifying equipment	75	7	17	**76**	74	0	14	**87**
Scheduling of meals	79	13	34	53	74	0	18	**82**
Modifying consistency of food or drink	70	9	13	**79**	72	1	13	**86**
Modifying other aspects of food or drink	76	5	21	**74**	73	3	22	**75**
Modifying placement of food	60	10	22	**68**	70	3	19	**79**
Enhancing communication	75	4	20	**76**	73	0	18	**82**
Visual supports	71	11	37	52	71	0	37	63
Responding to a child's cues	64	5	13	**83**	71	1	4	**94**
Pace of feeding	70	1	21	**77**	71	0	4	**96**
Physical supports	54	13	15	**72**	67	3	28	**69**
Medication	49	8	14	**78**	70	0	14	**86**
Energy supplements	45	13	24	62	68	0	27	**74**
Vitamin or nutritional supplements	60	7	25	**68**	68	0	32	**68**
Oral and sensory desensitisation	68	6	20	**72**	72	10	22	**68**
Oral-motor exercises	59	7	20	**73**	68	27	34	40
Graded exposure to new food	73	6	29	66	72	0	15	**85**
Graded exposure to new textures	75	3	29	**68**	73	0	19	**81**
Changing behaviour at mealtimes	76	7	37	57	73	4	33	63
Modelling	79	3	18	**80**	73	0	18	**82**
Training to self-feed	69	6	26	**68**	72	4	49	47
Support for parents	74	3	16	**81**	73	0	16	**84**
Sharing information	76	0	11	**90**	73	0	6	**95**
Psychological support for child	65	9	19	**72**	70	3	34	63

The above figures are for those respondents who were able to score individual interventions (i.e. those who had used them) and therefore do not include those who reported being unable to score or for whom data was missing. Percentages were rounded to the nearest whole number and therefore rounded totals are occasionally different to 100%. Scores above the consensus rating of ≥67% are shown in bold.

Supplementary Table 4. Parents' and health professionals' ratings of interventions on Round 2 of the Delphi Survey

Intervention	Parents N=61				Health professionals N=61			
	n	Not Important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %	n	Not important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %
Modifying environment	60	2	22	**77**	57	0	5	**95**
Positioning	54	2	2	**96**	57	0	0	**100**
Modifying equipment	54	4	4	**93**	57	0	11	**90**
Scheduling of meals	58	5	45	50	57	0	18	**83**
Modifying consistency of food or drink	56	2	20	**79**	54	0	4	**96**
Modifying other aspects of food or drink	59	3	10	**86**	57	2	16	**83**
Modifying placement of food	48	2	23	**75**	57	0	11	**90**
Enhancing communication	59	2	12	**86**	57	0	11	**90**
Visual supports	54	4	44	52	57	2	26	**72**
Responding to a child's cues	55	0	7	**93**	56	0	4	**96**
Pace of feeding	56	0	11	**89**	56	0	0	**100**
Physical supports	44	5	14	**82**	57	4	16	**81**
Medication	47	4	9	**87**	57	2	7	**91**
Energy supplements	42	2	29	**69**	55	0	27	**73**
Vitamin or nutritional supplements	54	0	15	**85**	55	0	26	**75**
Oral and sensory desensitisation	54	6	13	**82**	57	9	16	**75**
Oral-motor exercises	50	4	26	**70**	57	35	30	35
Graded exposure to new food	60	3	27	**70**	57	4	12	**84**
Graded exposure to new textures	59	2	2	**76**	57	0	19	**81**
Changing behaviour at mealtimes	59	7	36	58	57	2	42	56
Modelling	60	2	22	**77**	57	0	18	**83**
Training to self-feed	56	5	39	55	56	4	50	46
Support for parents	60	2	3	**95**	56	0	4	**96**
Sharing information	60	0	0	**100**	57	0	4	**97**
Psychological support for child	52	4	19	**77**	56	4	38	59

The above figures are for those respondents who were able to score individual interventions (i.e. those who had used them) and therefore do not include those who reported being unable to score or for whom data was missing. Percentages were rounded to the nearest whole number and therefore rounded totals are occasionally different to 100%. Scores above the consensus rating of ≥67% are shown in bold.

Supplementary Table 5. Parents’ and health professionals’ ratings of outcomes on Round 1 of the Delphi Survey

	Parents N=81				Health professionals N=76			
	n	Not Important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %	n	Not important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %
General Health	80	1	10	**89**	76	0	7	**93**
Weight	80	6	41	53	76	4	45	51
Height	78	18	51	31	76	18	50	32
Growth	79	0	25	**75**	76	0	24	**76**
Nutrition	81	0	11	**89**	76	0	3	**97**
Child’s enjoyment of mealtimes	80	1	16	**83**	76	0	9	**91**
Parent’s enjoyment of mealtimes	81	7	51	42	76	0	24	**76**
Quality of life of child	81	1	4	**95**	75	0	8	**92**
Quality of life of family	81	1	21	**78**	75	0	13	**87**
Mental health of parent	81	0	17	**83**	76	0	16	**84**
Safety	78	0	3	**97**	75	0	3	**97**
Oral-motor control	76	0	13	**87**	74	3	23	**74**
Efficiency	80	13	44	44	75	5	35	60
Independence	80	13	28	60	75	3	**67**	31
Variety	81	5	44	51	75	4	**73**	23
Amount	81	4	35	62	75	5	55	40
Appetite	81	3	38	59	75	3	53	44
Mealtime behaviour	80	14	45	41	74	10	61	30
Mealtime Interaction	79	4	35	61	74	1	18	**81**
Social participation	80	4	46	50	74	1	22	**77**
Child’s understanding of mealtimes	80	4	45	51	74	4	45	51
Parent’s understanding of child’s EDSD	80	1	10	**89**	72	1	10	**89**

The above figures are for those respondents who were able to score individual interventions (i.e. those who had used them) and therefore do not include those who reported being unable to score or for whom data was missing. Percentages were rounded to the nearest whole number and therefore rounded totals are occasionally different to 100%. Scores above the consensus rating of ≥67% are shown in bold.

Supplementary Table 6. Parents' and health professionals' ratings of outcomes on Round 2 of the Delphi Survey

Outcome	Parents N=61				Health professionals N=61			
	n	Not Important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %	n	Not important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %
General Health	61	0	3	**97**	61	0	2	**98**
Weight	61	0	66	34	61	0	53	48
Height	61	13	**75**	12	61	13	**75**	12
Growth	61	0	18	**82**	61	0	12	**89**
Nutrition	61	0	5	**95**	60	0	2	**98**
Child's enjoyment of mealtimes	61	0	10	**90**	60	0	2	**98**
Parent's enjoyment of mealtimes	61	8	53	39	59	0	22	**78**
Quality of life of child	61	0	2	**98**	59	0	0	**100**
Quality of life of family	61	0	10	**90**	58	0	3	**97**
Mental health of parent	61	0	7	**93**	58	0	3	**97**
Safety	61	0	0	**100**	58	0	0	**100**
Oral-motor control	56	0	14	**86**	58	0	28	**72**
Efficiency	60	13	**70**	17	57	5	49	46
Independence	61	10	48	43	58	3	**69**	28
Variety	61	3	**71**	26	57	4	**84**	12
Amount	61	0	48	53	56	2	**73**	25
Appetite	61	2	53	46	56	2	61	38
Mealtime behaviour	61	8	57	34	57	5	**68**	26
Mealtime Interaction	60	5	30	65	57	0	21	**79**
Social participation	60	10	37	53	57	2	25	**74**
Child's understanding of mealtimes	60	3	38	58	57	2	58	40
Parent's understanding of child's EDSD	60	0	5	**95**	57	0	7	**93**

The above figures are for those respondents who were able to score individual interventions (i.e. those who had used them) and therefore do not include those who reported being unable to score or for whom data was missing. Percentages were rounded to the nearest whole number and therefore rounded totals are occasionally different to 100%. Scores above the consensus rating of ≥67% are shown in bold.

FEEDS Delphi Survey – Round 1

You are invited to take part in the next step of the national UK research study "FEEDS: Focus on Early Eating, Drinking and Swallowing review".

Below is our information sheet with more information about the survey. Once you have read this information, if you would like to take part please click the forward arrow at the bottom of this text.

What is the study about?

The study aims to find out about strategies to improve eating, drinking and swallowing difficulties that can be used at home by parents of young children with developmental difficulties. "Strategies" refers to the things people do to help children with eating and drinking difficulties.

Why have I been invited to take part?

You may have previously completed one of our surveys – thank you again for doing so. You expressed an interest in being contacted about this survey as part of our ongoing research.

What will I have to do?

This is a Delphi Survey, which is a way to seek agreement between different groups of people. This type of survey has stages, where families and clinicians complete questions two or three times. Each round takes approximately 15 minutes to complete. Here is some information about each round:

Round 1 – You will be presented with a list of strategies for improving eating and drinking and a list of potential benefits of the strategies (we are calling these outcomes).

You will be asked to rate how important you think that each strategy and outcome is on a scale from 1 (not important) to 9 (essential). There will be an option to add any strategies or outcomes you think are missing and make any further comments you have.

Round 2/3 – A few weeks after completing the previous round, you will receive another email asking you to complete the survey again.

You will be asked to complete the ratings again.

It is important that, if you agree to take part, you complete all rounds of the survey.

How do I take part?

To enter the survey, please click the forward arrow at the bottom of this page. We plan for this round (round 1) of the survey to be open for 3 weeks.

What happens to the information I give in the study?

Your responses to the survey will be confidential. By completing the survey, you are consenting to take part in this stage of the research. If you wish to stop the survey at any time, you can do so. We will keep the information you have already given us unless you tell us that you no longer want to take part and would like to have your information removed completely.

We will store any personal information you share with us safely and securely at Newcastle University (in line with data protection laws). All personal information shared with us will be destroyed 6-12 months after the end of the study (currently planned to be December 2019).

The information provided during the survey will be looked at by the research team and may also be looked at by Newcastle upon Tyne Hospitals NHS Foundation Trust or representatives from the regulatory authorities.

What happens if I take part?

At the end of the final round of the survey, you will be entered into a prize draw to **win a £100 voucher**. There will be five vouchers available for parents / carers and five for healthcare professionals. We will also send you a summary of the results of this survey and the wider study.

After the final round of the survey, we will be running two meetings where we draw together all the study findings, and make conclusions. These meetings are expected to take place in April / May 2019. We would like parents, professionals and researchers to take part in the meetings. We expect to invite 10-20 people to each meeting. If you would like to participate, you can let us know this at the end of round two of the survey.

Who is leading the study?

The study is being led by clinical researchers at Newcastle University and Newcastle upon Tyne Hospitals NHS Trust in collaboration with colleagues from Exeter, Sussex and London. The study is funded by the National Institute for Health Research Health Technology Assessment (NIHR HTA) programme – the research part of the NHS.

Who do I contact if I'd like more information about the research?

If you have questions please contact Dr Helen Taylor, FEEDS researcher via email at Feeds@ncl.ac.uk by telephone on 0191 2821379 or by post at:

Dr Helen Taylor
Development and Disability Group, Newcastle University
3rd Floor, Sir James Spence Institute
Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne
NE1 4LP

Or see the project website: https://tinyurl.com/FEEDSstudy

What if I have concerns or a complaint?

If you have any concerns about this research and would like to discuss them further, please contact Dr Helen Taylor, who will discuss your concerns with Dr Jeremy Parr or Dr Lindsay Pennington who are leading the study.

If you prefer to raise your concerns with someone not involved with the study, you can contact the Patient Advice and Liaison Service (PALS). This service is confidential and can be contacted on Freephone: 0800 032 0202.

Alternatively if you wish to make a formal complaint, you can contact the Patient Relations Department through any of the details below:

Telephone: 0191 223 1382 or 0191 223 1454
Email: patient.relations@nuth.nhs.uk
Address: Patient Relations Department
The Newcastle upon Tyne Hospitals NHS Foundation Trust
The Freeman Hospital
Newcastle upon Tyne
NE7 7DN

Thank you very much for your help with this research.

Thank you for taking the time to read the information about the study.

To give your consent to take part, please respond to the following statement:

I have read the information about the study and I agree to take part by completing the survey.

Please note that you cannot take part without answering the question. If you don't agree to take part, we would like to thank you for your time reading this.

○ Agree

○ Disagree

Welcome to the FEEDS Delphi Survey and thank you for taking part.

This is the **first** part of the survey.

In this survey, eating, drinking and swallowing difficulties are referred to as "eating and drinking difficulties". The term "strategy" or "strategies" is used to describe what some people might call intervention, therapy, treatment, advice or things that help including self-help. The potential benefits of the strategies are referred to as "outcomes".

The survey is divided into 2 sections:

- In part A we ask about a list of **outcomes** related to improved eating and drinking.

- In part B, we ask about a list of **strategies** to improve eating and drinking.

The lists have been developed from information gathered during our research so far.

Q1 Please describe yourself:

○ Parent / guardian / caregiver

○ Healthcare professional

Q2 What is your age (in years)?

○ Under 20

○ 21-30

○ 31-40

○ 41-50

○ 51-60

○ 61-70

○ Over 70

Q3 What is your gender?

○ Male

○ Female

○ Prefer not to say

○ Other (please specify): ____

Q4

For parents / guardians / caregivers: Where do you live?

For healthcare professionals: Where do you work?

○ North East England

○ North West England

○ Yorkshire and Humber

○ East Midlands

○ West Midlands

○ South East including London

○ South West

○ Scotland

○ Northern Ireland

○ Wales

Q5 What is your ethnicity?

○ White

○ Black/ African / Caribbean / Black British

○ Asian / Asian British

○ Mixed / Multiple Ethnic Groups

○ Other Ethnic Group

○ Prefer not to say

Q6 How did you hear about the survey?

○ Took part in previous FEEDS survey

○ Voluntary Organisation / Charity

○ ASD-UK / Daslne database

○ Parental network / support group

○ Professional Organisation / Network

○ Other (please specify): ____

Q7 Children can have different types of eating and drinking difficulties. Which difficulties are you answering the survey about?

○ **Physical difficulties** (Reduced control of the muscles of the lips, tongue, mouth and throat) (1)

○ **Non-physical difficulties** (Sensory or behavioural issues leading to restricted or selective eating and rituals associated with food or mealtimes) (2)

○ **Both physical and non-physical difficulties** (3)

Part A: Outcomes

Strategies for improving eating and drinking are tested to see if they work.

We want to know what we should measure in order to see if a strategy works - what are the most important outcomes or results?

Please tell us how important you think each of the following outcomes are.

Q8 **Please tell us how important you think each of the outcomes below are:**

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not Applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
General health A child's overall health	○	○	○	○	○	○	○	○	○	○
Weight How much a child weighs	○	○	○	○	○	○	○	○	○	○
Height How tall a child is	○	○	○	○	○	○	○	○	○	○
Growth A change in a child's growth, including height and weight	○	○	○	○	○	○	○	○	○	○
Nutrition A child's level of energy and nutrients for healthy growth	○	○	○	○	○	○	○	○	○	○

Q9 Please provide any additional comments you have on any of the outcomes listed above here:

____

Q10 **Please tell us how important you think each of the outcomes below are:**

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not Applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Child's enjoyment of mealtimes	○	○	○	○	○	○	○	○	○	○
Parent or caregiver's enjoyment of mealtimes	○	○	○	○	○	○	○	○	○	○
Quality of life of child How satisfied a child feels about their life	○	○	○	○	○	○	○	○	○	○
Quality of life of family How satisfied other family members feel about their (own) lives	○	○	○	○	○	○	○	○	○	○
Mental health of parent or caregiver A parent / caregiver's mood and emotional wellbeing	○	○	○	○	○	○	○	○	○	○

Q11 Please provide any additional comments you have on any of the outcomes listed above here:

____

Q12 **Please tell us how important you think each of the outcomes below are:**

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not Applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Safety A child's ability to eat and drink safely without choking or aspirating	○	○	○	○	○	○	○	○	○	○
Oral motor control A child's ability to control the movement of their mouth, jaw, tongue or lips and swallow	○	○	○	○	○	○	○	○	○	○
Efficiency A child's ability to eat and drink at a reasonable pace	○	○	○	○	○	○	○	○	○	○

Q13 Please provide any additional comments you have on any of the outcomes listed above here:

____

Q14 **Please tell us how important you think each of the outcomes below are:**

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not Applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Independence A child's ability to feed themselves	○	○	○	○	○	○	○	○	○	○
Variety The range of foods or liquids a child eats or drinks	○	○	○	○	○	○	○	○	○	○
Amount The amount of food or liquid a child eats or drinks per day	○	○	○	○	○	○	○	○	○	○
Appetite A child's level of hunger and desire for food / drink	○	○	○	○	○	○	○	○	○	○

Q15 Please provide any additional comments you have on any of the outcomes listed above here:

____

Q16 **Please tell us how important you think each of the outcomes below are:**

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not Applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Mealtime behaviour A child behaving appropriately during meals	○	○	○	○	○	○	○	○	○	○
Mealtime interaction The interaction between a child and the person feeding them at mealtimes	○	○	○	○	○	○	○	○	○	○
Social participation A child's overall involvement at mealtimes	○	○	○	○	○	○	○	○	○	○

Q17 Please provide any additional comments you have on any of the outcomes listed above here:

____

Q18 **Please tell us how important you think each of the outcomes below are:**

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not Applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Child's understanding A child's understanding of mealtime activities and routines	○	○	○	○	○	○	○	○	○	○
Parent or caregiver's understanding A parent / caregiver's insight into their child's eating and drinking difficulties	○	○	○	○	○	○	○	○	○	○

Q19 Please provide any additional comments you have on any of the outcomes listed above here:

Q20 Please provide any additional outcomes you think are important or essential here:

Part B: Strategies

A variety of strategies are used to improve eating and drinking difficulties in children with developmental difficulties.

We found that strategies are often used together as part of an 'intervention package'. We want to know which strategies are important to include in that 'intervention package'.

For each of the strategies listed, please tell us how important you think it is that the strategy is included as part of an 'intervention package' for children with eating and drinking difficulties.

Many of the strategies involve teaching children new behaviour and rely on techniques such as prompting or giving praise for the behaviours we want to encourage. Because these techniques apply to so many of the strategies, we have not included them in the descriptions below.

Please answer based on your own knowledge and experience, and what you may know of other people's experiences.

Q21 Please rate how important it is that each of the strategies below is included as part of an 'intervention package' for children with eating and drinking difficulties:

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Modifying environment Changing the physical or social setting at mealtimes (e.g. reducing distractions such as levels of noise; using distractions to reduce a child's attention on their food)	○	○	○	○	○	○	○	○	○	○
Positioning Ensuring a child is in the best position to eat and drink food safely and efficiently (e.g. a child sitting upright; providing support for head control)	○	○	○	○	○	○	○	○	○	○
Modifying equipment Using different spoons, forks, plates, cups, bottles etc (e.g. doidy cup; plastic spoon)	○	○	○	○	○	○	○	○	○	○
Scheduling of meals Setting the timing of mealtimes to encourage a child's appetite and establish a mealtime routine (e.g. spreading meals / snacks throughout the day; setting a 30 minutes limit for mealtimes)	○	○	○	○	○	○	○	○	○	○

Q22 Please provide any additional comments you have on any of the strategies listed above here:

Q23 Please rate how important it is that each of the strategies below is included as part of an 'intervention package' for children with eating and drinking difficulties:

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Modifying consistency of food or drink Changing the consistency of a child's food or drink (e.g. pureeing food; thickening food or drink)	○	○	○	○	○	○	○	○	○	○
Modifying other aspects of food or drink Changing the temperature, taste amount or presentation of a child's food or drink (e.g. presenting different foods so they do not touch each other; mixing liked foods with disliked foods)	○	○	○	○	○	○	○	○	○	○
Modifying placement of food Changing where food is placed in a child's mouth to help chewing or swallowing (e.g. placing food to the side of the mouth)	○	○	○	○	○	○	○	○	○	○

Q24 Please provide any additional comments you have on any of the strategies listed above here:

Q25 Please rate how important it is that each of the strategies below is included as part of an 'intervention package' for children with eating and drinking difficulties:

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Enhancing communication Improving communication between a child and the person feeding them during mealtimes (e.g. offering choices of food to a child; a child using eye pointing or signs or symbols to ask for specific food or drink)	○	○	○	○	○	○	○	○	○	○
Visual supports Use of pictures, a "countdown clock", or social stories to increase a child's understanding of what happens during mealtimes (e.g. showing a child pictures of what food will be on their plate; showing a child a story to explain what will happen during a mealtime)	○	○	○	○	○	○	○	○	○	○
Responding to a child's cues for feeding Helping people to recognise the signs that a child is ready to take another mouthful of food or drink (e.g. looking for breath alterations or repeated swallows from a child to indicate a lack of readiness)	○	○	○	○	○	○	○	○	○	○
Pace of feeding Changing the speed at which each mouthful of food or drink is taken by a child (e.g. slowing pace down to prevent overfilling of a child's mouth)	○	○	○	○	○	○	○	○	○	○

Q26 Please provide any additional comments you have on any of the strategies listed above here:

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Q27 Please rate how important it is that each of the strategies below is included as part of an 'intervention package' for children with eating and drinking difficulties:

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Medication Any medication (e.g. for epilepsy, pain, drooling, tone, gastroesophageal reflux)	○	○	○	○	○	○	○	○	○	○
Energy supplements Any energy or calorie supplement given orally or via feeding tube	○	○	○	○	○	○	○	○	○	○
Vitamin or nutritional supplements Any supplements given or changes to a child's diet to increase the vitamins or nutrients in their diet	○	○	○	○	○	○	○	○	○	○

Q28 Please provide any additional comments you have on any of the strategies listed above here:

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Q29 Please rate how important it is that each of the strategies below is included as part of an 'intervention package' for children with eating and drinking difficulties:

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Physical support Giving direct physical support to a child when eating or drinking to improve the movements needed to bite, chew and swallow (e.g. placing a thumb underneath the chin to help a child close their mouth)	○	○	○	○	○	○	○	○	○	○
Oral and sensory desensitisation Activities aimed at reducing a child's adverse reactions to different sensory experiences linked to eating and drinking (e.g. face massage; chewing non-food items such as a chewy 'toothbrush')	○	○	○	○	○	○	○	○	○	○
Oral motor exercises Exercises done with a child to improve the control of their mouth, jaw, tongue or lips (e.g. a child moving a non-food item with their tongue; a child sucking through a straw)	○	○	○	○	○	○	○	○	○	○

Q30 Please provide any additional comments you have on any of the strategies listed above here:

____

Q31 Please rate how important it is that each of the strategies below is included as part of an 'intervention package' for children with eating and drinking difficulties:

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Graded exposure to new food Activities aimed at gradually exposing a child to new or disliked foods and drinks (e.g. messy play activities involving a child touching new or disliked foods; using small steps towards a child accepting new or disliked foods such as licking the food or putting it in their mouth with no expectation to swallow)	○	○	○	○	○	○	○	○	○	○
Graded exposure to new textures Activities aimed at gradually introducing a child to more challenging food textures and fluid consistencies (e.g. messy play activities involving a child touching new or disliked textures; using small steps to introduce a child to lumpy food or foods that require chewing)	○	○	○	○	○	○	○	○	○	○

Q32 Please provide any additional comments you have on any of the strategies listed above here:

Q33 Please rate how important it is that each of the strategies below is included as part of an 'intervention package' for children with eating and drinking difficulties:

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Changing behaviour at mealtimes Strategies to encourage a child to behave appropriately at mealtimes (e.g. a child sitting down ready to eat; a child staying seated for the meal)	○	○	○	○	○	○	○	○	○	○
Modelling Giving a child the opportunity to learn from others by eating and drinking with them (e.g. sitting a child with other children or family members at mealtimes)	○	○	○	○	○	○	○	○	○	○
Training to self-feed Teaching a child to feed themselves (e.g. placing a hand over a child's hand to help guide the food into their mouth)	○	○	○	○	○	○	○	○	○	○

Q34 Please provide any additional comments you have on any of the strategies listed above here:

Q35 Please rate how important it is that each of the strategies below is included as part of an 'intervention package' for children with eating and drinking difficulties:

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not applicable / Not relevant'

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Support for parents Help for parents around their child's eating and drinking difficulties (e.g. counselling; parent support groups)	○	○	○	○	○	○	○	○	○	○
Sharing information Any information shared to help parents and professionals understand a child's difficulties with eating and drinking (e.g. professionals teaching parents and school staff about a child's physical or sensory difficulties; parents helping professionals understand what's important about mealtimes in their family)	○	○	○	○	○	○	○	○	○	○
Psychological support for children Psychological help for a child (e.g. counselling)	○	○	○	○	○	○	○	○	○	○

Q36 Please provide any additional comments you have on any of the strategies listed above here:

Q37 Please provide any additional strategies you think are important or essential here:

FEEDS Delphi Survey - Round 2

Thank you for taking part in the first round of the FEEDS Delphi survey.

The FEEDS study aims to find out about strategies that parents of young children with developmental difficulties can use at home to help improve children's eating, drinking and swallowing difficulties.

As a reminder, in our study eating, drinking and swallowing difficulties are referred to as "eating and drinking difficulties". The term "strategy" or "strategies" is used to describe what some people might call intervention, therapy, treatment, advice or things that help including self-help. The potential benefits of the strategies are referred to as "outcomes".

This is the **second** round of the survey.

A Delphi survey is a way to seek agreement between different groups of people. It's like having a discussion but through a survey instead of face to face. The Delphi survey will help us to reach conclusions about which outcomes and strategies should be examined in future research.

In this survey, you will be shown how parents and professionals rated items in the first round. As you will see from the graphs, there are high levels of agreement between people for some items and for others there is not agreement. We are asking you to re-rate each outcome and strategy in light of this information and we will see if there is more agreement this time.

Like last time, the survey is divided into 2 sections:

- In part A, we show you how parents and professionals rated a list of **outcomes** related to improved eating and drinking.
- In part B, we show you how parents and professionals rated a list of **strategies** to improve eating and drinking.

Part A: Outcomes

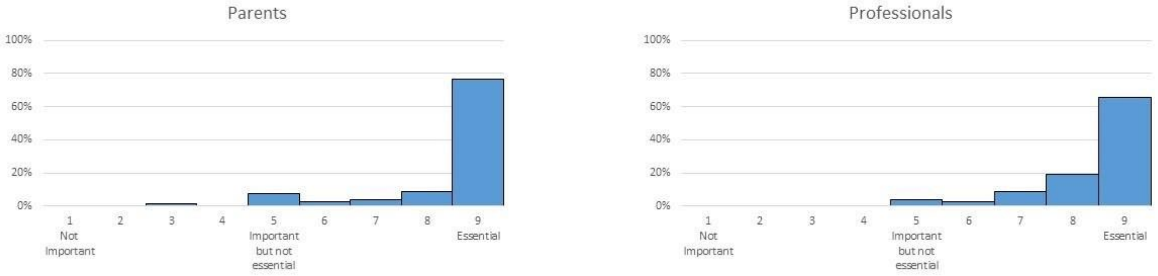
For each outcome, you will be shown graphs of how parents and professionals rated that outcome in the previous round. You will then be asked to **re-rate how important you think the outcome is**.

If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not applicable / Not relevant'.

If you would like to add any additional outcomes or comment further on those listed, please do so in the text boxes. If you made comments in the previous round, we will take account of these so you do not need to repeat these comments again on this survey. Thank you.

General Health

The graphs below show how important parents and professionals rated 'General Health' as an outcome.



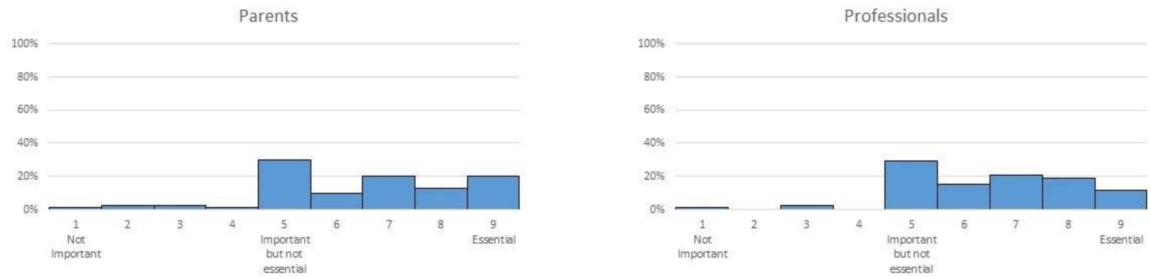
Q1_1 Now that you know this, please re-rate how important you think this outcome is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
General health A child's overall health	○	○	○	○	○	○	○	○	○	○

Q1_2 Please provide any additional comments you have about this outcome here:

Weight

The graphs below show how important parents and professionals rated 'Weight' as an outcome.



Q2_1 Now that you know this, please re-rate how important you think this outcome is.

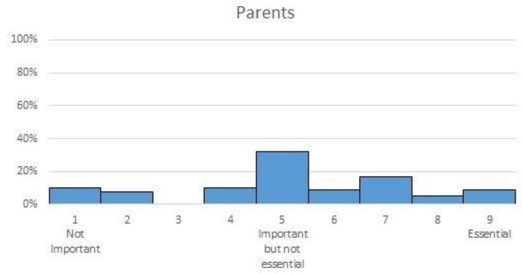
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Weight How much a child weighs	○	○	○	○	○	○	○	○	○	○

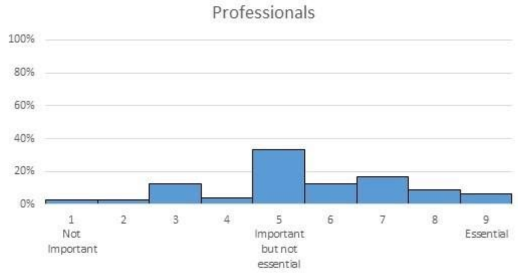
Q2_2 Please provide any additional comments you have about this outcome here:

____

Height

The graphs below show how important parents and professionals rated 'Height' as an outcome.





Q3_1 Now that you know this, please re-rate how important you think this outcome is.

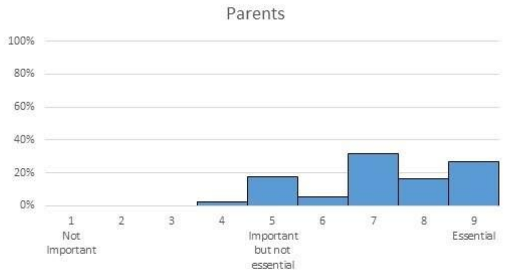
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Height How tall a child is	○	○	○	○	○	○	○	○	○	○

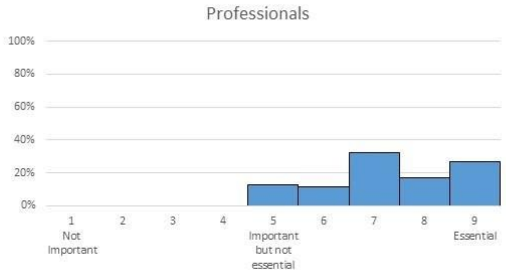
Q3_2 Please provide any additional comments you have about this outcome here:

____

Growth

The graphs below show how important parents and professionals rated 'Growth' as an outcome.





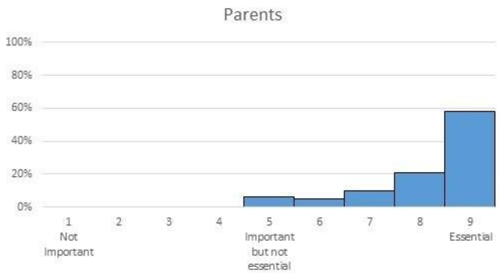
Q4_1 Now that you know this, please re-rate how important you think this outcome is.

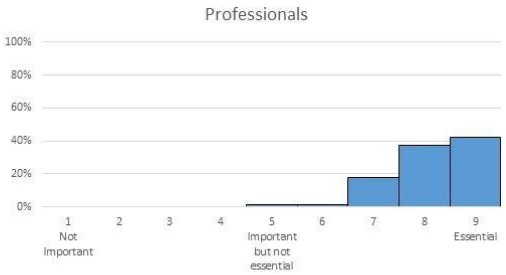
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Growth A change in a child's growth, including height and weight	○	○	○	○	○	○	○	○	○	○

Q4_2 Please provide any additional comments you have about this outcome here:

Nutrition

The graphs below show how important parents and professionals rated 'Nutrition' as an outcome.





Q5_1 Now that you know this, please re-rate how important you think this outcome is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Nutrition A child's level of energy and nutrients for healthy growth	○	○	○	○	○	○	○	○	○	○

Q5_2 Please provide any additional comments you have about this outcome here:

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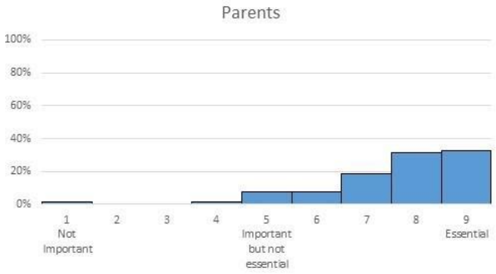
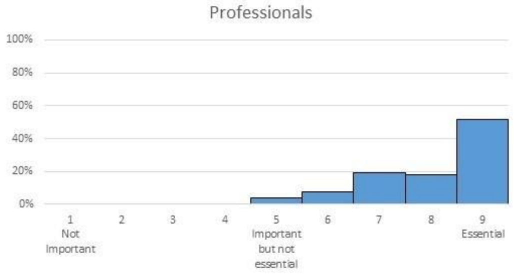
Child's Enjoyment of Mealtimes

The graphs below show how important parents and professionals rated 'Child's Enjoyment of Mealtimes' as an outcome.





Q6_1 Now that you know this, please re-rate how important you think this outcome is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Child's enjoyment of mealtimes	○	○	○	○	○	○	○	○	○	○

Q6_2 Please provide any additional comments you have about this outcome here:

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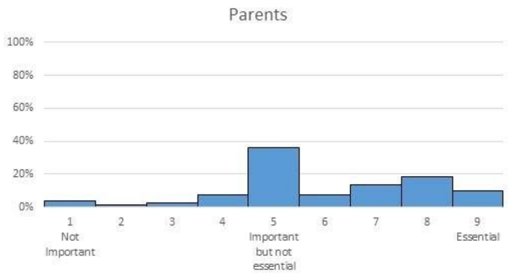
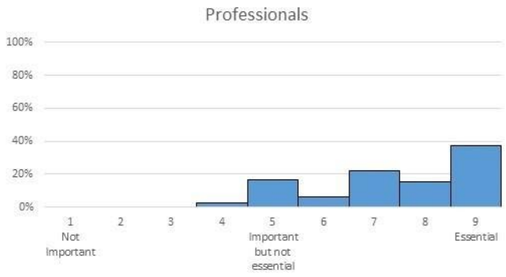
Parent or Caregiver's Enjoyment of Mealtimes

The graphs below show how important parents and professionals rated 'Parent or Caregiver's Enjoyment of Mealtimes' as an outcome.





Q7_1 Now that you know this, please re-rate how important you think this outcome is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Parent or caregiver's enjoyment of mealtimes	○	○	○	○	○	○	○	○	○	○

Q7_2 Please provide any additional comments you have about this outcome here:

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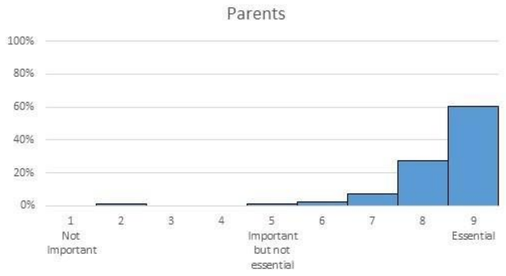
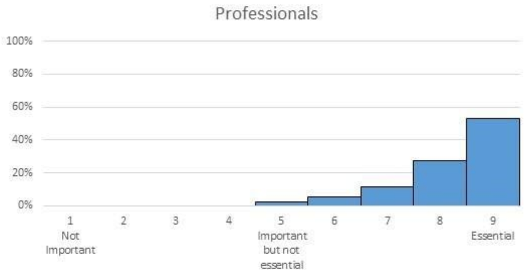
Quality of Life of Child

The graphs below show how important parents and professionals rated 'Quality of Life of Child' as an outcome.





Q8_1 Now that you know this, please re-rate how important you think this outcome is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Quality of life of child How satisfied a child feels about their life	○	○	○	○	○	○	○	○	○	○

Q8_2 Please provide any additional comments you have about this outcome here:

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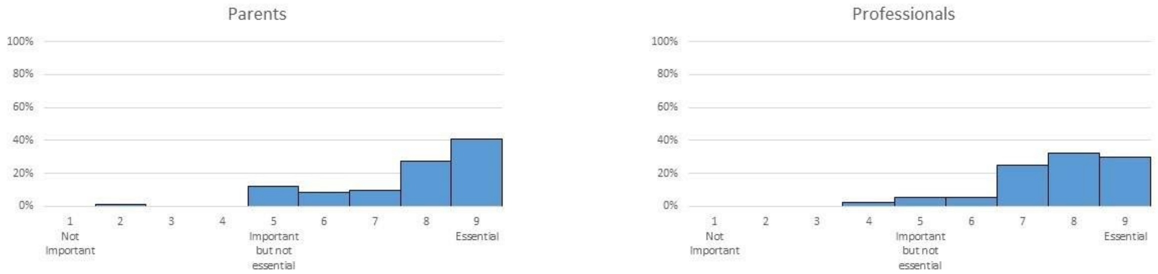
Quality of Life of Family

The graphs below show how important parents and professionals rated 'Quality of Life of Family' as an outcome.



Q9_1 Now that you know this, please re-rate how important you think this outcome is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Quality of life of family How satisfied other family members feel about their (own) lives	○	○	○	○	○	○	○	○	○	○

Q9_2 Please provide any additional comments you have about this outcome here:

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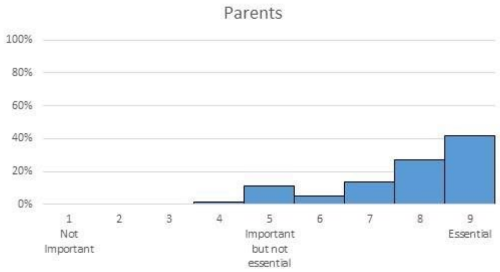
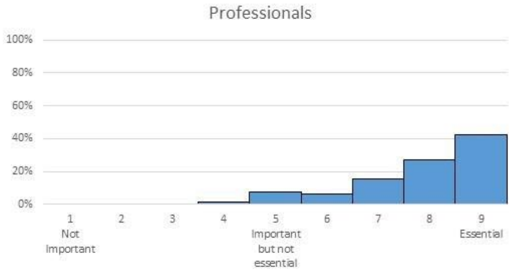
Mental Health of Parent or Caregiver

The graphs below show how important parents and professionals rated 'Mental Health of Parent or Caregiver' as an outcome.





Q10_1 Now that you know this, please re-rate how important you think this outcome is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Mental health of parent or caregiver A parent / caregiver's mood and emotional wellbeing	○	○	○	○	○	○	○	○	○	○

Q10_2 Please provide any additional comments you have about this outcome here:

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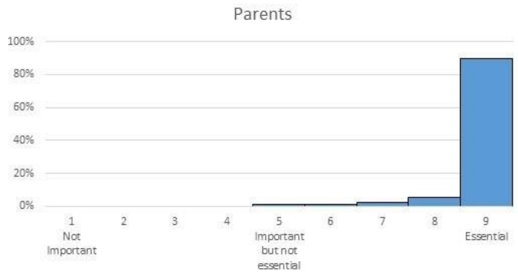
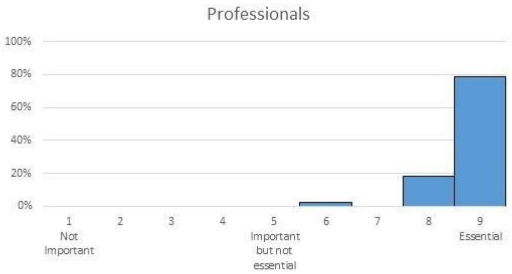
Safety

The graphs below show how important parents and professionals rated 'Safety' as an outcome.





Q11_1 Now that you know this, please re-rate how important you think this outcome is.

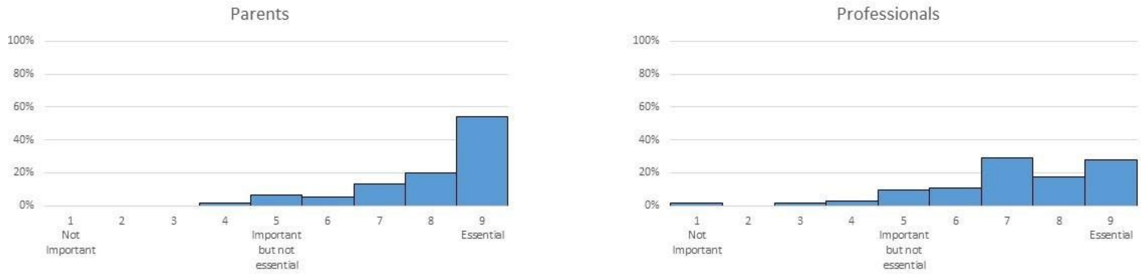
	Not important 1	2 (2)	3 (3)	4 (4)	Important but not essential 5 (5)	6 (6)	7 (7)	8 (8)	Essential 9 (9)	Not applicable / Not relevant (10)
Safety A child's ability to eat and drink safely without choking or aspirating	○	○	○	○	○	○	○	○	○	○

Q11_2 Please provide any additional comments you have about this outcome here:

____

Oral Motor Control

The graphs below show how important parents and professionals rated 'Oral Motor Control' as an outcome.



Q12_1 Now that you know this, please re-rate how important you think this outcome is.

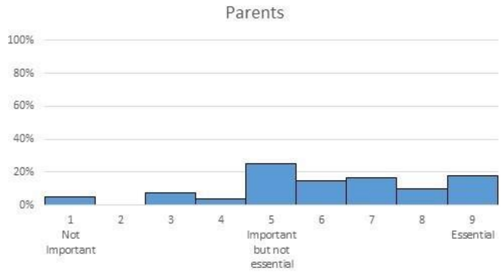
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Oral motor control A child's ability to control the movement of their mouth, jaw, tongue or lips and swallow	○	○	○	○	○	○	○	○	○	○

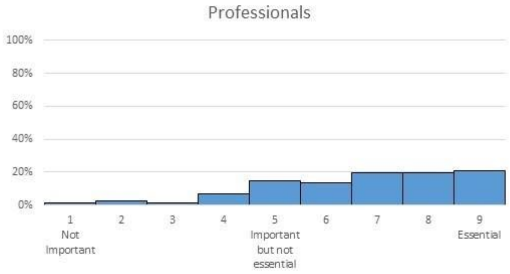
Q12_2 Please provide any additional comments you have about this outcome here:

____

Efficiency

The graphs below show how important parents and professionals rated 'Efficiency' as an outcome.





Q13_1 Now that you know this, please re-rate how important you think this outcome is.

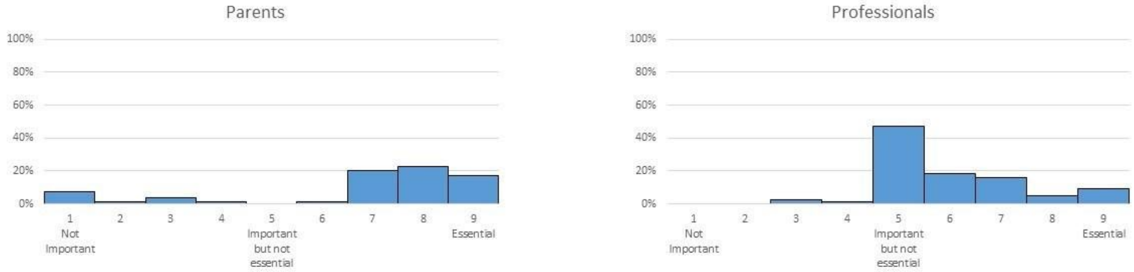
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Efficiency A child's ability to eat and drink at a reasonable pace	○	○	○	○	○	○	○	○	○	○

Q13_2 Please provide any additional comments you have about this outcome here:

____

Independence

The graphs below show how important parents and professionals rated 'Independence' as an outcome.



Q14_1 Now that you know this, please re-rate how important you think this outcome is.

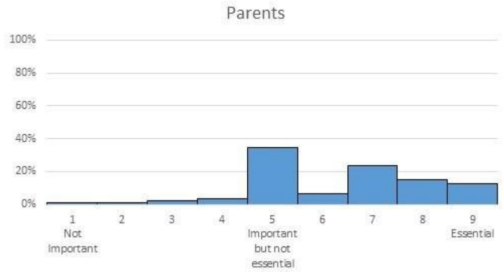
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Independence A child's ability to feed themselves	○	○	○	○	○	○	○	○	○	○

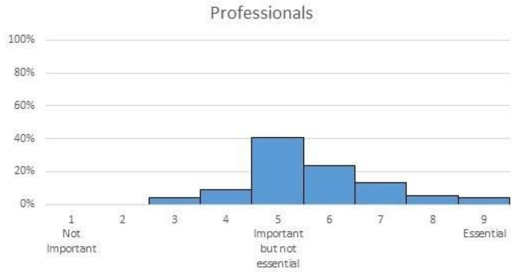
Q14_2 Please provide any additional comments you have about this outcome here:

____

Variety

The graphs below show how important parents and professionals rated 'Variety' as an outcome.





Q15_1 Now that you know this, please re-rate how important you think this outcome is.

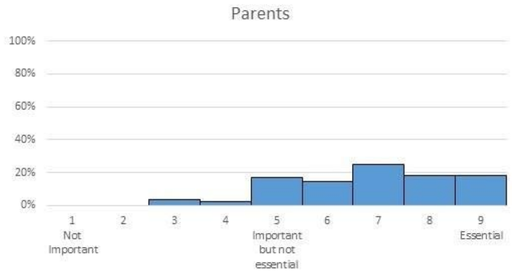
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Variety The range of foods or liquids a child eats or drinks	○	○	○	○	○	○	○	○	○	○

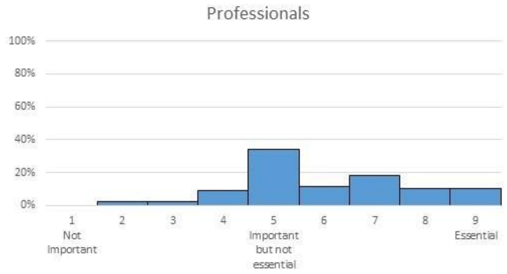
Q15_2 Please provide any additional comments you have about this outcome here:

____

Amount

The graphs below show how important parents and professionals rated 'Amount' as an outcome.





Q16_1 Now that you know this, please re-rate how important you think this outcome is.

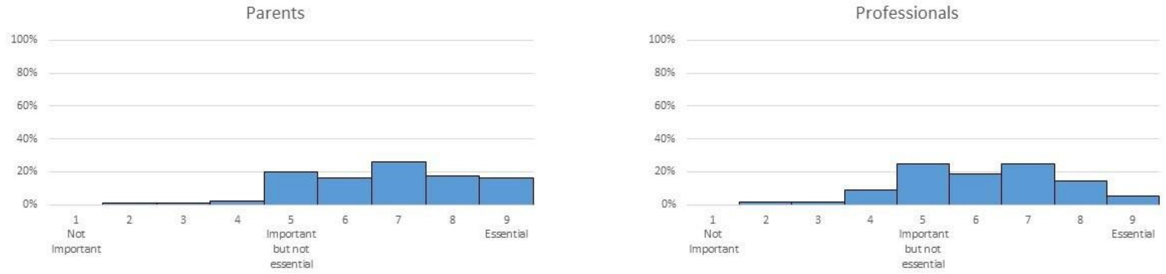
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Amount The amount of food or liquid a child eats or drinks per day	○	○	○	○	○	○	○	○	○	○

Q16_2 Please provide any additional comments you have about this outcome here:

____

Appetite

The graphs below show how important parents and professionals rated 'Appetite' as an outcome.



Q17_1 Now that you know this, please re-rate how important you think this outcome is.

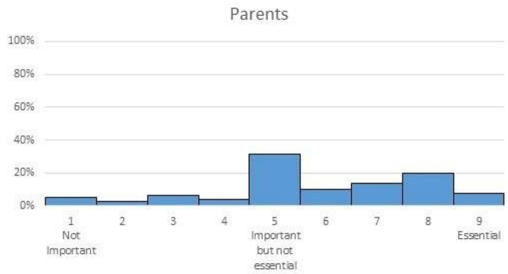
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Appetite A child's level of hunger and desire for food or drink	○	○	○	○	○	○	○	○	○	○

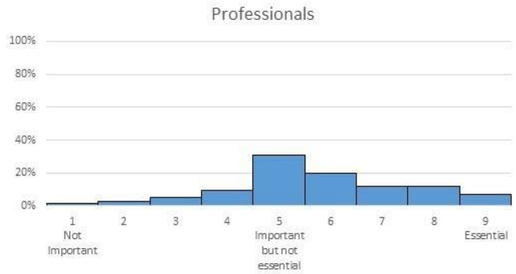
Q17_2 Please provide any additional comments you have about this outcome here:

____

Mealtime Behaviour

The graphs below show how important parents and professionals rated 'Mealtime Behaviour' as an outcome.





Q18_1 Now that you know this, please re-rate how important you think this outcome is.

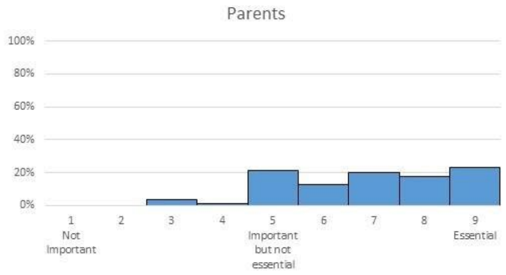
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Mealtime behaviour A child behaving appropriately during meals	○	○	○	○	○	○	○	○	○	○

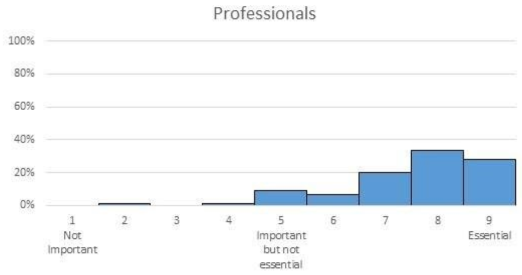
Q18_2 Please provide any additional comments you have about this outcome here:

____

Mealtime Interaction

The graphs below show how important parents and professionals rated 'Mealtime Interaction' as an outcome.





Q19_1 Now that you know this, please re-rate how important you think this outcome is.

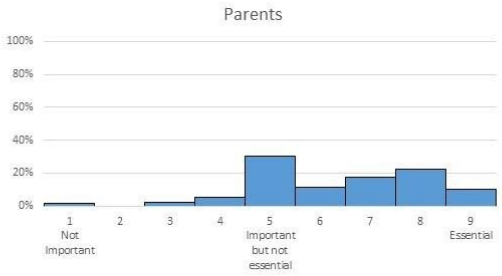
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Mealtime interaction The interaction between a child and the person feeding them at mealtimes	○	○	○	○	○	○	○	○	○	○

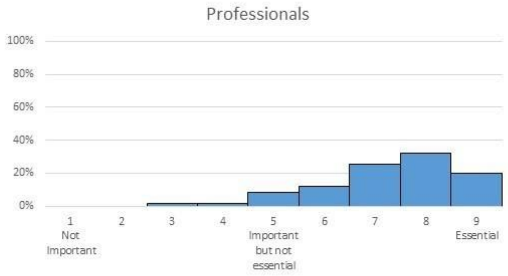
Q19_2 Please provide any additional comments you have about this outcome here:

____

Social Participation

The graphs below show how important parents and professionals rated 'Social Participation' as an outcome.





Q20_1 Now that you know this, please re-rate how important you think this outcome is.

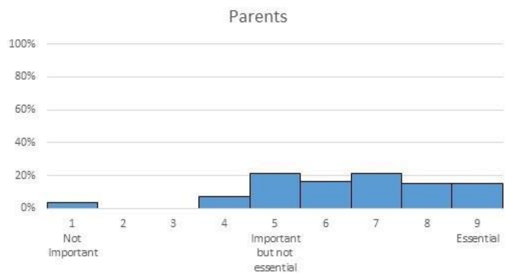
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Social participation A child's involvement in social activities around eating and drinking	○	○	○	○	○	○	○	○	○	○

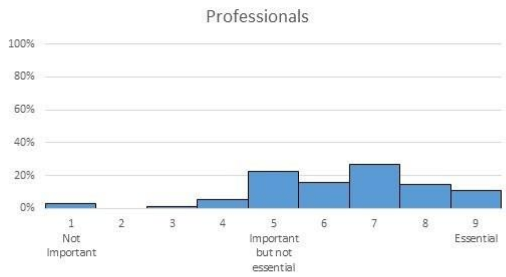
Q20_2 Please provide any additional comments you have about this outcome here:

____

Child's Understanding

The graphs below show how important parents and professionals rated 'Child's Understanding' as an outcome.





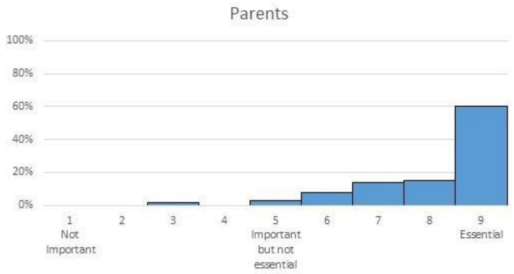
Q21_1 Now that you know this, please re-rate how important you think this outcome is.

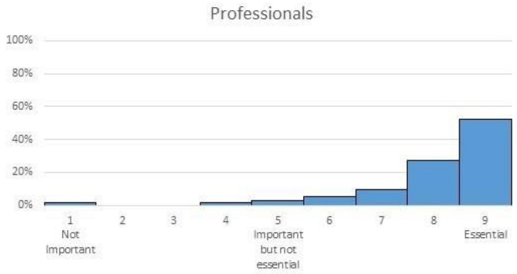
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Child's understanding A child's understanding of mealtime activities and routines	○	○	○	○	○	○	○	○	○	○

Q21_2 Please provide any additional comments you have about this outcome here:

Parent or Caregiver's Understanding

The graphs below show how important parents and professionals rated 'Parent or Caregiver's Understanding' as an outcome.





Q22_1 Now that you know this, please re-rate how important you think this outcome is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Parent or caregiver's understanding A parent or caregiver's insight into their child's eating and drinking difficulties	○	○	○	○	○	○	○	○	○	○

Q22_2 Please provide any additional comments you have about this outcome here:

____

Q23
Please provide any additional outcomes you think are important or essential here:

If you provided any additional outcomes in the previous round, we will take account of these so you do not need to repeat these comments again on this survey. Thank you.

____

Part B: Strategies

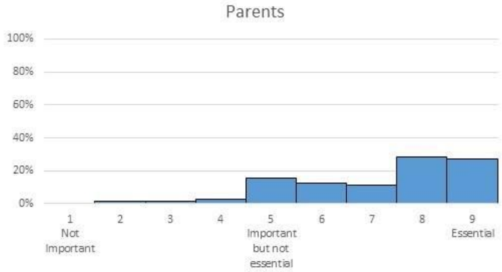
For each strategy, you will be shown graphs of how parents and professionals rated that strategy in the previous round. You will then be asked to **re-rate how important you think it is that the strategy is included in an 'intervention package' for children with eating and drinking difficulties**.

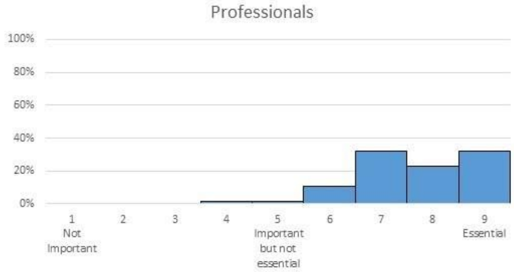
If you feel unable to comment based on your knowledge and / or experience or feel the item is not relevant or not applicable to you, please select 'Not applicable / Not relevant'.

If you would like to add any additional strategies or comment further on those listed, please do so in the text boxes. If you made comments in the previous round, we will take account of these so you do not need to repeat these comments again on this survey. Thank you.

Modifying Environment

The graphs below show how important parents and professionals rated 'Modifying Environment' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





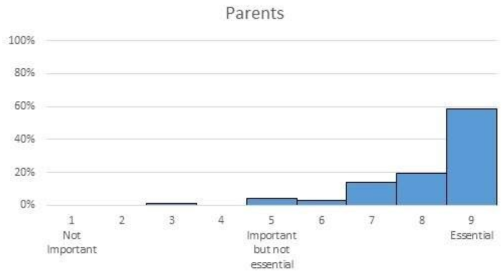
Q24_1 Now that you know this, please re-rate how important you think it is that this strategy is included in an 'intervention package' for children with eating and drinking difficulties.

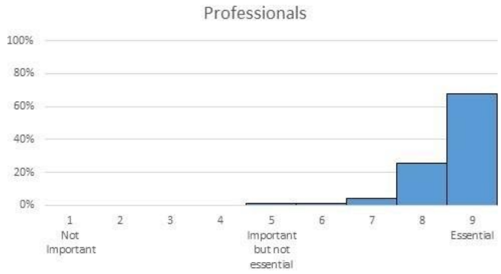
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential	Not applicable / Not relevant
Modifying environment Changing the physical or social setting at mealtimes (e.g. reducing distractions such as levels of noise; using distractions to reduce a child's attention on their food)	○	○	○	○	○	○	○	○	○	○

Q24_2 Please provide any additional comments you have about this strategy here:

Positioning

The graphs below show how important parents and professionals rated 'Positioning' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q25_1 Now that you know this, please re-rate how important you think this strategy is.

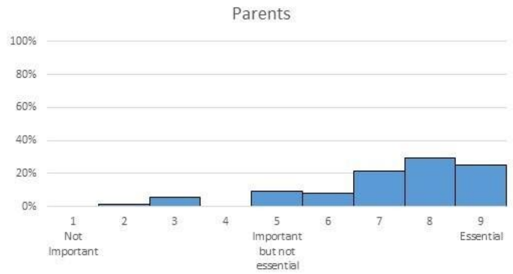
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Positioning Ensuring a child is in the best position to eat and drink food safely and efficiently (e.g. a child sitting upright; providing support for head control)	○	○	○	○	○	○	○	○	○	○

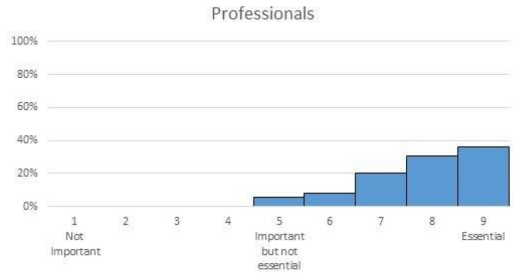
Q25_2 Please provide any additional comments you have about this strategy here:

____

Modifying Equipment

The graphs below show how important parents and professionals rated 'Modifying Equipment' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q26_1 Now that you know this, please re-rate how important you think this strategy is.

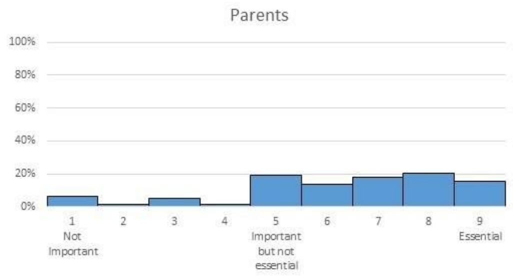
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Modifying equipment Using different spoons, forks, plates, cups, bottles etc (e.g. doidy cup; plastic spoon)	○	○	○	○	○	○	○	○	○	○

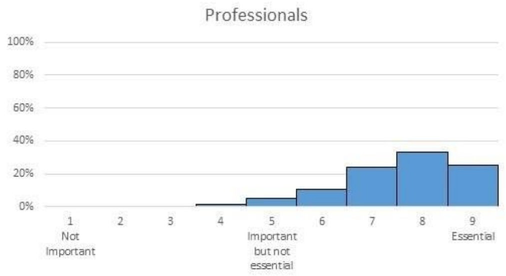
Q26_2 Please provide any additional comments you have about this strategy here:

____

Scheduling of meals

The graphs below show how important parents and professionals rated 'Scheduling of Meals' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q27_1 Now that you know this, please re-rate how important you think this strategy is.

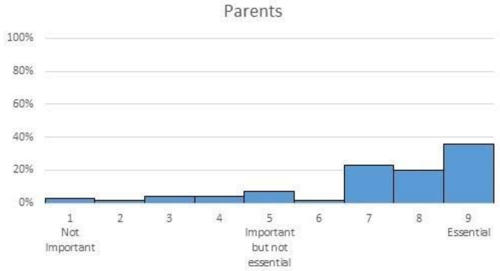
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Scheduling of meals Setting the timing of mealtimes to encourage a child's appetite and establish a mealtime routine (e.g. spreading meals / snacks throughout the day; setting a 30 minute limit for mealtimes)	○	○	○	○	○	○	○	○	○	○

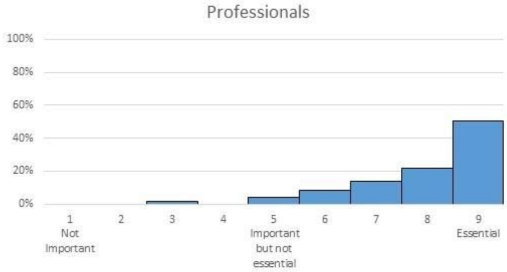
Q27_2 Please provide any additional comments you have about this strategy here:

____

Modifying Consistency of Food or Drink

The graphs below show how important parents and professionals rated 'Modifying Consistency of Food or Drink' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q28_1 Now that you know this, please re-rate how important you think this strategy is.

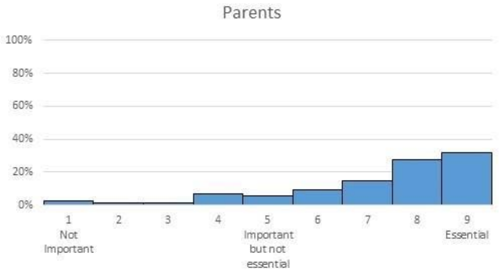
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Modifying consistency of food or drink Changing the consistency of a child's food or drink (e.g. pureeing food; thickening food or drink)	○	○	○	○	○	○	○	○	○	○

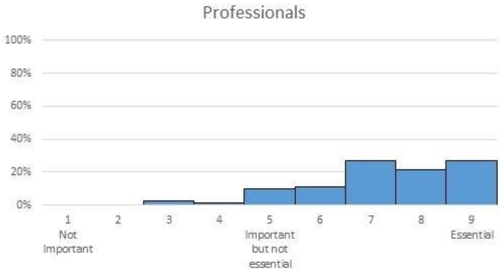
Q28_2 Please provide any additional comments you have about this strategy here:

____

Modifying Other Aspects of Food or Drink

The graphs below show how important parents and professionals rated 'Modifying Other Aspects of Food or Drink' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





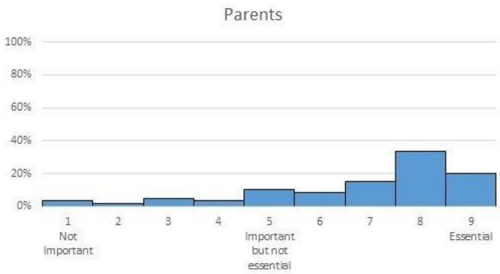
Q29_1 Now that you know this, please re-rate how important you think this strategy is.

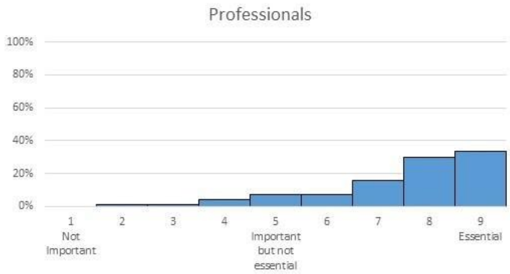
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Modifying other aspects of food or drink Changing the temperature, taste, amount or presentation of a child's food or drink (e.g. presenting different foods so they do not touch each other; mixing liked foods with disliked foods)	○	○	○	○	○	○	○	○	○	○

Q29_2 Please provide any additional comments you have about this strategy here:

Modifying Placement of Food

The graphs below show how important parents and professionals rated 'Modifying Placement of Food' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q30_1 Now that you know this, please re-rate how important you think this strategy is.

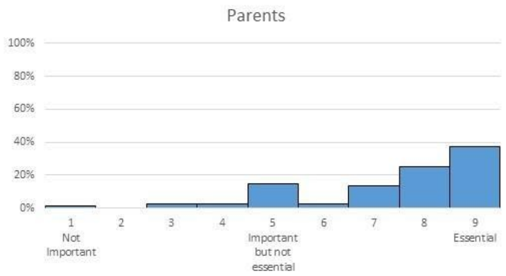
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Modifying placement of food Changing where the food is placed in a child's mouth to help chewing or swallowing (e.g. placing food to the side of the mouth)	○	○	○	○	○	○	○	○	○	○

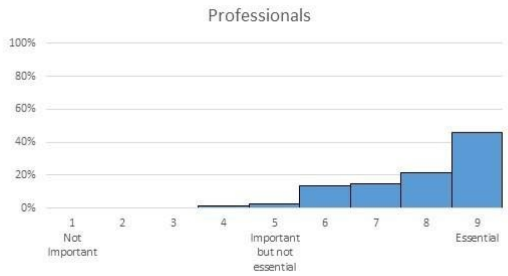
Q30_2 Please provide any additional comments you have about this strategy here:

____

Enhancing Communication

The graphs below show how important parents and professionals rated 'Enhancing Communication' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q31_1 Now that you know this, please re-rate how important you think this strategy is.

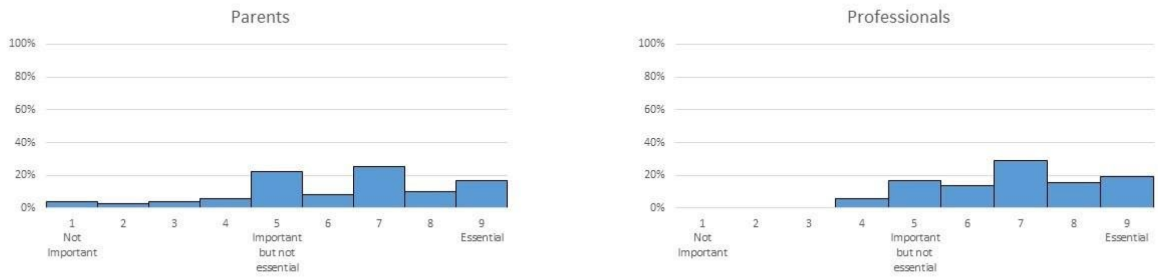
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Enhancing communication Improving communication between a child and the person feeding them during mealtimes (e.g. offering choices of food to a child; a child using eye pointing or signs or symbols to ask for specific food or drink)	○	○	○	○	○	○	○	○	○	○

Q31_2 Please provide any additional comments you have about this strategy here:

____

Visual supports

The graphs below show how important parents and professionals rated 'Visual Supports' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.



Q32_1 Now that you know this, please re-rate how important you think this strategy is.

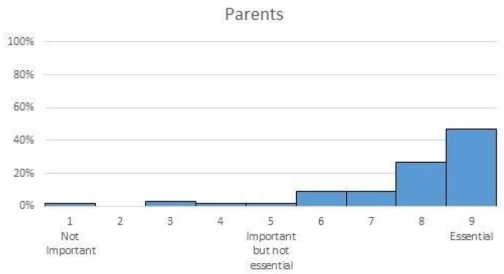
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Visual supports Use of pictures, a "countdown clock", or social stories to increase a child's understanding of what happens during mealtimes (e.g. showing a child pictures of what food will be on their plate; showing a child a story to explain what will happen during a mealtime)	○	○	○	○	○	○	○	○	○	○

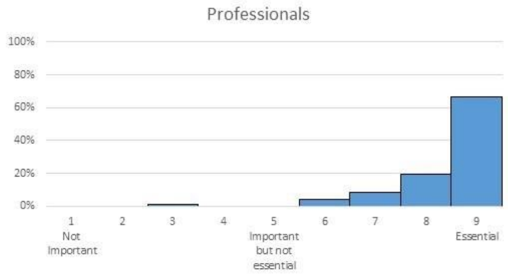
Q32_2 Please provide any additional comments you have about this strategy here:

____

Responding to a Child's Cues for Feeding

The graphs below show how important parents and professionals rated 'Responding to a Child's Cues for Feeding' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q33_1 Now that you know this, please re-rate how important you think this strategy is.

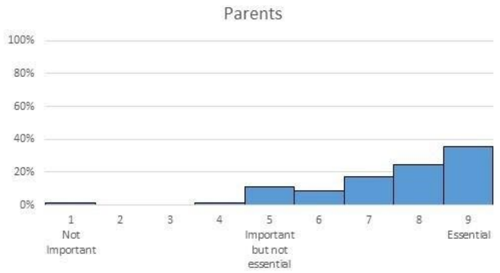
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Responding to a child's cues for feeding Helping people to recognise the signs that a child is ready to take another mouthful of food or drink (e.g. looking for breath alterations or repeated swallows from a child to indicate a lack of readiness)	○	○	○	○	○	○	○	○	○	○

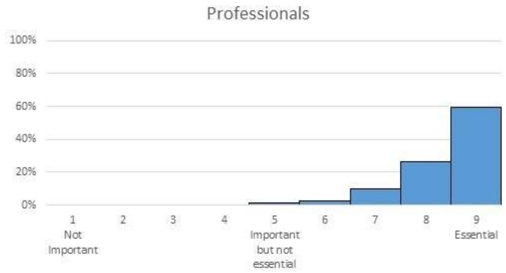
Q33_2 Please provide any additional comments you have about this strategy here:

____

Pace of Feeding

The graphs below show how important parents and professionals rated 'Pace of Feeding' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q34_1 Now that you know this, please re-rate how important you think this strategy is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Pace of feeding Changing the speed at which each mouthful of food or drink is taken by a child (e.g. slowing pace down to prevent overfilling of a child's mouth)	○	○	○	○	○	○	○	○	○	○

Q34_2 Please provide any additional comments you have about this strategy here:

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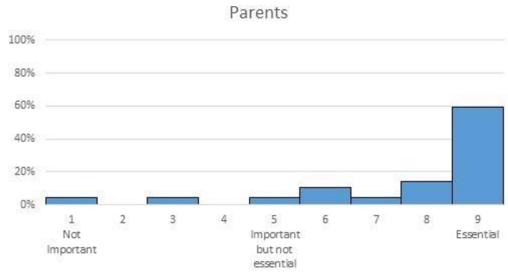
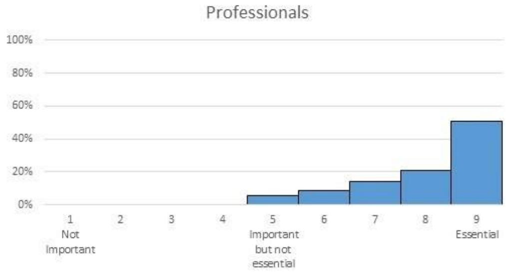
Medication

The graphs below show how important parents and professionals rated 'Medication' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q35_1 Now that you know this, please re-rate how important you think this strategy is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevan
Medication Any medication (e.g. for epilepsy, pain, drooling, tone, gastroesophageal reflux)	○	○	○	○	○	○	○	○	○	○

Q35_2 Please provide any additional comments you have about this strategy here:

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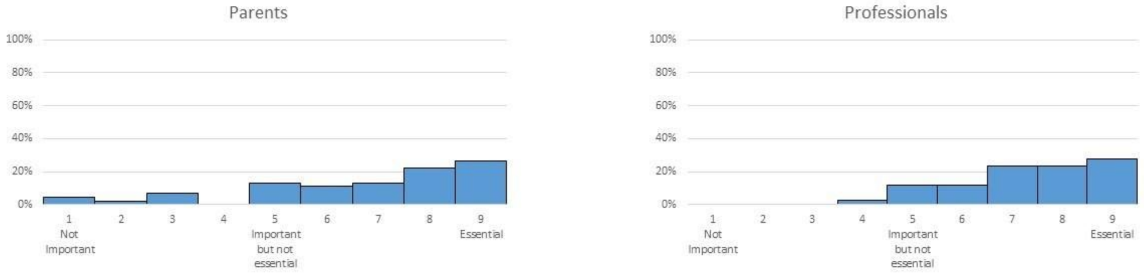
Energy Supplements

The graphs below show how important parents and professionals rated 'Energy Supplements' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.



Q36_1 Now that you know this, please re-rate how important you think this strategy is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Energy supplements Any energy or calorie supplement given orally or via feeding tube	○	○	○	○	○	○	○	○	○	○

Q36_2 Please provide any additional comments you have about this strategy here:

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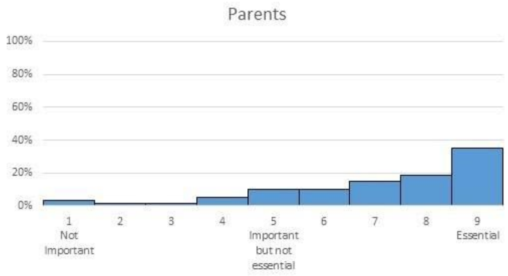
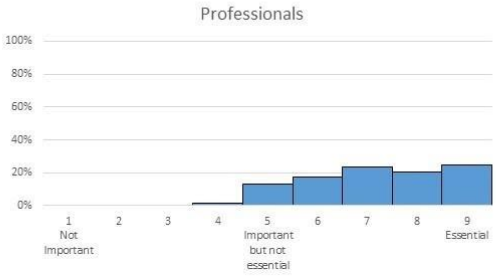
Vitamin or Nutritional Supplements

The graphs below show how important parents and professionals rated 'Vitamin or Nutritional Supplements' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q37_1 Now that you know this, please re-rate how important you think this strategy is.

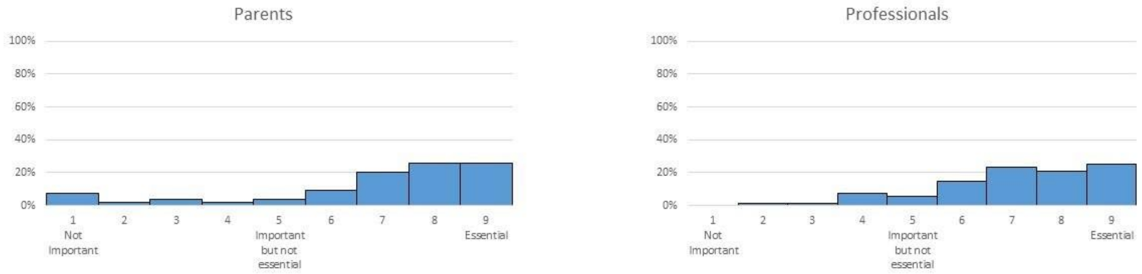
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Vitamin or nutritional supplements Any supplements given or changes to a child's diet to increase the vitamins or nutrients in their diet	○	○	○	○	○	○	○	○	○	○

Q37_2 Please provide any additional comments you have about this strategy here:

____

Physical Support

The graphs below show how important parents and professionals rated 'Physical Support' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.



Q38_1 Now that you know this, please re-rate how important you think this strategy is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Physical support Giving direct physical support to a child when eating or drinking to improve the movements needed to bite, chew and swallow (e.g. placing a thumb underneath the chin to help a child close their mouth)	○	○	○	○	○	○	○	○	○	○

Q38_2 Please provide any additional comments you have about this strategy here:

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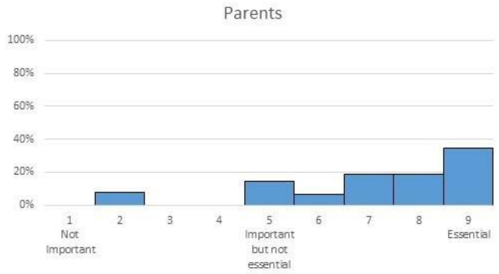
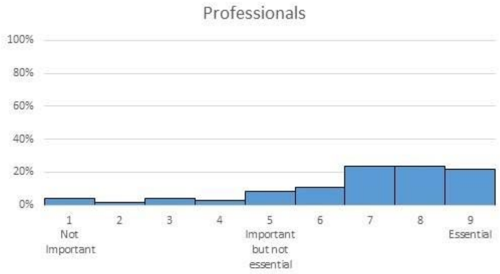
Oral and Sensory Desensitisation

The graphs below show how important parents and professionals rated 'Oral and Sensory Desensitisation' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q39_1 Now that you know this, please re-rate how important you think this strategy is.

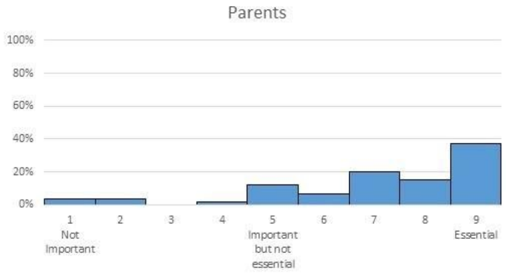
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Oral and sensory desentisation Activities aimed at reducing a child's adverse reactions to different sensory experiences linked to eating and drinking (e.g. face massage; chewing non-food items such as a chewy 'toothbrush')	○	○	○	○	○	○	○	○	○	○

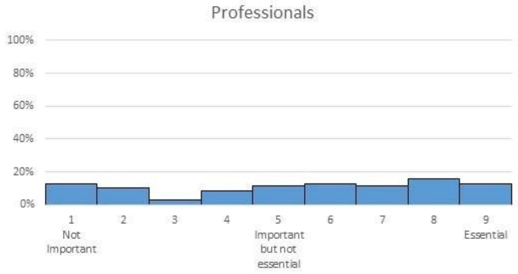
Q39_2 Please provide any additional comments you have about this strategy here:

____

Oral Motor Exercises

The graphs below show how important parents and professionals rated 'Oral Motor Exercises' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q40_1 Now that you know this, please re-rate how important you think this strategy is.

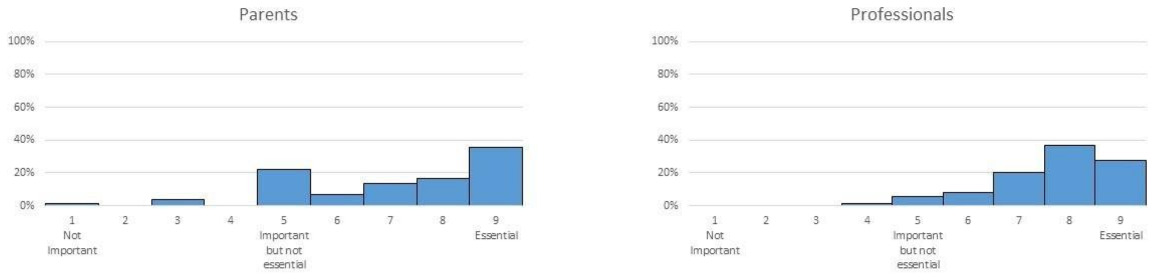
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Oral motor exercises Exercises done with a child to improve the control of their mouth, jaw, tongue or lips (e.g. a child moving a non-food item with their tongue; a child sucking through a straw)	○	○	○	○	○	○	○	○	○	○

Q40_2 Please provide any additional comments you have about this strategy here:

____

Graded Exposure to New Food

The graphs below show how important parents and professionals rated 'Graded Exposure to New Food' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.



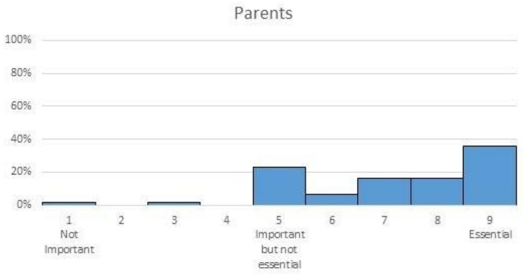
Q41_1 Now that you know this, please re-rate how important you think this strategy is.

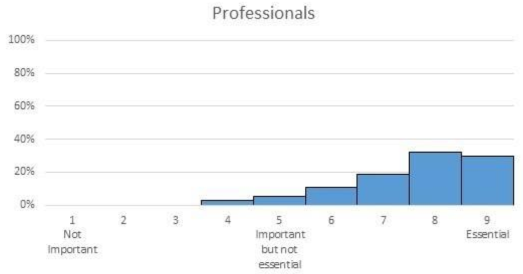
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Graded exposure to new food Activities aimed at gradually exposing a child to new or disliked foods and drinks (e.g. messy play activities involving a child; touching new or disliked foods; using small steps towards a child accepting new or disliked foods such as licking the food or putting it in their mouth with no expectation to swallow	○	○	○	○	○	○	○	○	○	○

Q41_2 Please provide any additional comments you have about this strategy here:

Graded Exposure to New Textures

The graphs below show how important parents and professionals rated 'Graded Exposure to New Textures' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q42_1 Now that you know this, please re-rate how important you think this strategy is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Graded exposure to new textures Activities aimed at gradually introducing a child to more challenging food textures and fluid consistencies (e.g. messy play activities involving a child touching new or disliked textures; using small steps to introduce a child to lumpy food or foods that require chewing)	○	○	○	○	○	○	○	○	○	○

Q42_2 Please provide any additional comments you have about this strategy here:

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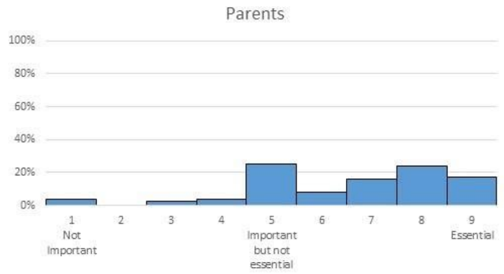
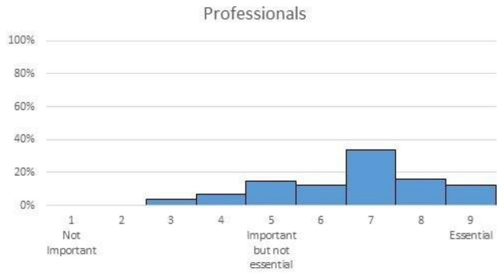
Changing Behaviour at Mealtimes

The graphs below show how important parents and professionals rated 'Changing Behaviour at Mealtimes' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





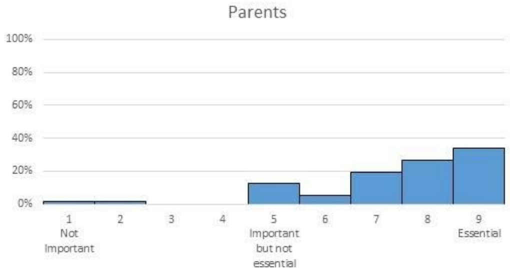
Q43_1 Now that you know this, please re-rate how important you think this strategy is.

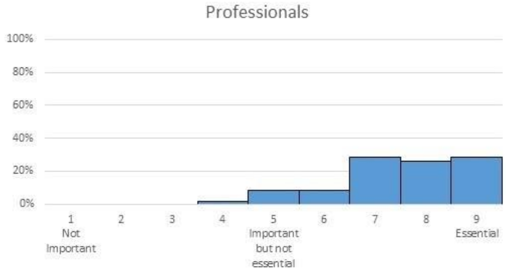
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Changing behaviour at mealtimes Strategies to encourage a child to behave appropriately at mealtimes (e.g. a child sitting down ready to eat; a child staying seated for the meal)	○	○	○	○	○	○	○	○	○	○

Q43_2 Please provide any additional comments you have about this strategy here:

Modelling

The graphs below show how important parents and professionals rated 'Modelling' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q44_1 Now that you know this, please re-rate how important you think this strategy is.

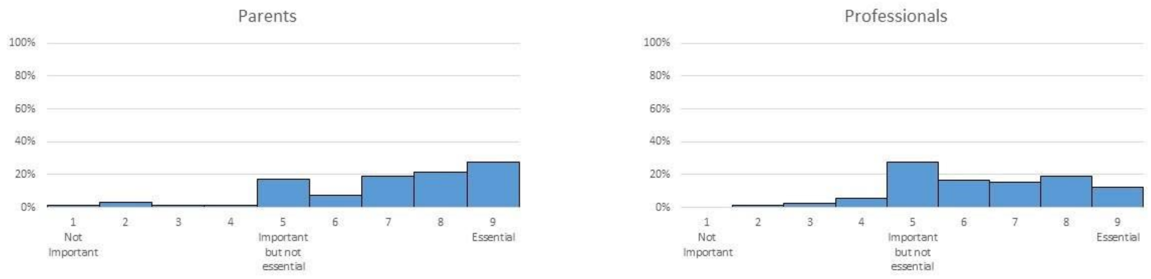
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Modelling Giving a child the opportunity to learn from others by eating and drinking with them (e.g. sitting a child with other children or family members at mealtimes)	○	○	○	○	○	○	○	○	○	○

Q44_2 Please provide any additional comments you have about this strategy here:

____

Training to Self-Feed

The graphs below show how important parents and professionals rated 'Training to Self-Feed' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.



Q45_1 Now that you know this, please re-rate how important you think this strategy is.

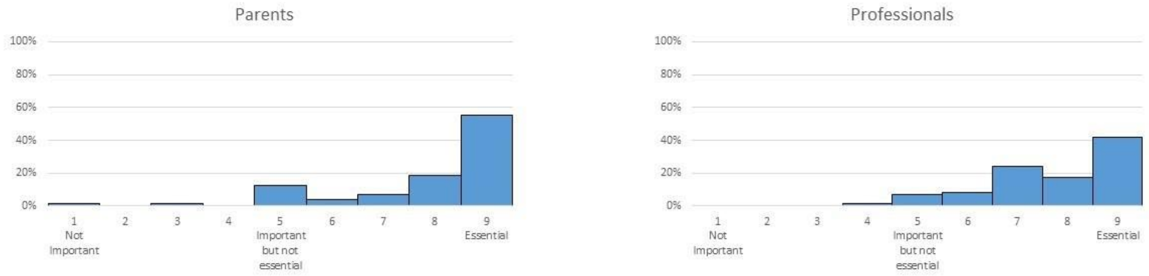
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Training to self feed Teaching a child to feed themselves (e.g. placing a hand over a child's hand to help guide the food into their mouth)	○	○	○	○	○	○	○	○	○	○

Q45_2 Please provide any additional comments you have about this strategy here:

____

Support for Parents

The graphs below show how important parents and professionals rated 'Support for Parents' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.



Q46_1 Now that you know this, please re-rate how important you think this strategy is.

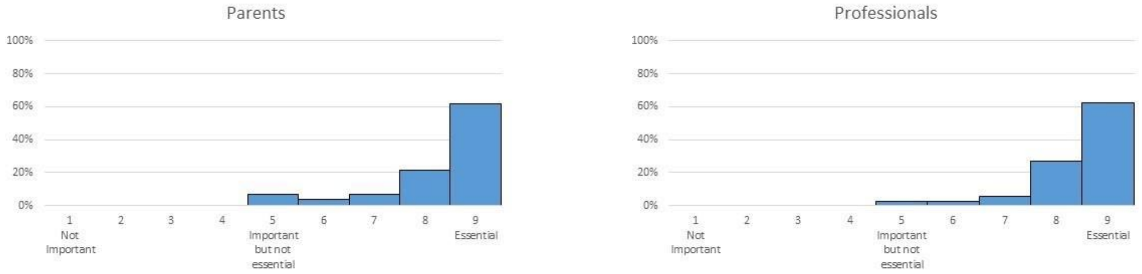
	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Support for parents Help for parents around their child's eating and drinking difficulties (e.g. counselling; parent support groups)	○	○	○	○	○	○	○	○	○	○

Q46_2 Please provide any additional comments you have about this strategy here:

____

Sharing Information

The graphs below show how important parents and professionals rated 'Sharing Information' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.



Q47_1 Now that you know this, please re-rate how important you think this strategy is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Sharing Information Any information shared to help parents and professionals understand a child's difficulties with eating and drinking (e.g. professionals teaching parents and school staff about a child's physical or sensory difficulties; parents helping professionals understand what's important about mealtimes in their family)	○	○	○	○	○	○	○	○	○	○

Q47_2 Please provide any additional comments you have about this strategy here:

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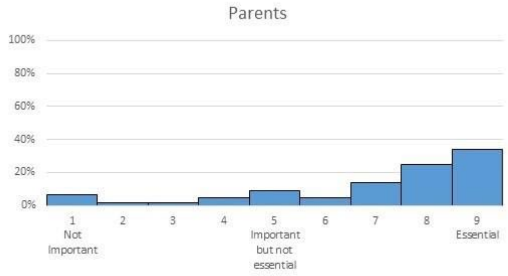
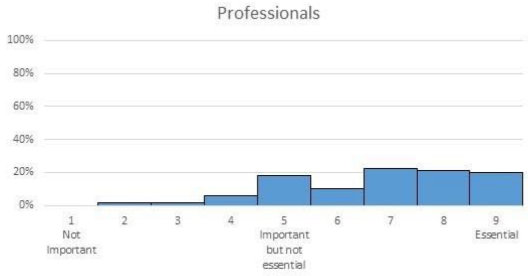
Psychological Support for Children

The graphs below show how important parents and professionals rated 'Psychological Support for Children' as a strategy to be included as part of an 'intervention package' for children with eating and drinking difficulties.





Q48_1 Now that you know this, please re-rate how important you think this strategy is.

	Not important 1	2	3	4	Important but not essential 5	6	7	8	Essential 9	Not applicable / Not relevant
Psychological support for children Psychological help for a child (e.g. counselling or cognitive behavioural therapy)	○	○	○	○	○	○	○	○	○	○

Q48_2 Please provide any additional comments you have about this strategy here:

____

Q49 Please provide any additional strategies you think are important or essential here:

If you provided any additional strategies in the previous round, we will take account of these so you do not need to repeat these comments again on this survey. Thank you.

What interventions, which could be delivered at home by parents, are available to improve eating in young children with neurodisability and are suitable for investigation in pragmatic trials?

Protocol Version:	Version 3
Chief Investigator:	Dr Jeremy Parr Clinical Senior Lecturer and Consultant, Paediatric Neurodisability
Sponsor:	Newcastle upon Tyne Hospitals NHS Foundation Trust

Registrations:

NIHR Reference:	15/156/02
IRAS Number:	215629
REC Reference:	17/WM/0439
R+D Reference:	08472

Sites:

Newcastle University

Exeter University

Chailey Heritage Clinical Services
Sussex Community NHS Trust

Guy's and St Thomas' NHS Foundation Trust

Study Start Date: 01/07/17

Likely End Date: 30/12/19

This study is funded by the NIHR HTA Programme (IRAS ID: 215629)

CONTENTS

5) Dissemination and Outputs

1) Summary of Research

Purpose:

To answer the question: What interventions, which could be delivered at home by parents, are available to improve eating in young children with neurodisability and are suitable for investigation in pragmatic trials?

Design:

Sequential mixed methods.

1. 1st round of focus groups: Professionals (health and education staff) and parents to gain a preliminary understanding of interventions offered to families of children with EDSD.
2. Survey 1: Professionals (health and education staff) and parents to identify current use of interventions that parents of young children with eating, drinking and swallowing difficulties can use at home.
3. Updating systematic reviews: Update three recent systematic reviews about interventions.
4. Evidence mapping: To identify potential interventions, outcomes and measurement tools and examine properties of the identified tools most frequently used and most valued to measure outcomes.
5. Evidence synthesis 1: Synthesis of evidence gathered through steps 1-4.
6. 2nd round of focus groups: Professionals (health and education staff), parents and young people to review evidence from the synthesis 1.
7. Delphi survey: To gain consensus on trial components.
8. Evidence synthesis 2: Synthesis of evidence gathered through steps 6-7.
9. Consensus workshops: To draw together all the available evidence to suggest a framework and outcomes for one or more trial(s) of interventions for children with EDSD.

Settings

NHS hospital and community services, family homes, education settings. UK parent and professional groups.

Current care pathways:

Interventions for Eating, Drinking and Swallowing Difficulties (EDSD) which young children in the UK currently receive.

Target population: Young children with physical or non-physical EDSD, their parents, and professionals that support them.

Inclusion criteria:

Young people with neurodisability and EDSD (aged 12-18 years); parents of young children with neurodisability and EDSD up to and including 12 years of age; parents who have been discharged home from neonatal units will be included; professionals who support children with neurodisability with EDSD.

Exclusion criterion:

Young children with progressive neurodisability and their parents; young children without neurodisability and their parents; parents of children who are inpatients postnatally.

Health Technologies being assessed:

Interventions to improve EDSD in young children with neurodisability

Measurement of costs and outcomes:

No health economic study will be undertaken but will be introduced to a future trial design

Sample size:

Aim 1 - Identifying current interventions and their evaluation:

Four focus groups (six participants each, 24 participants in total):

1. One for parents of young children with physical EDSD
2. One for parents of young children with non-physical EDSD
3. One for professionals of young children with physical EDSD (to include paediatrician, speech and language therapist, occupational therapist, dietician, gastroenterologist)
4. One for professionals of young children with non-physical EDSD

Survey: 200 UK parents of children with EDSD, 200 NHS professionals who recommend interventions for children with EDSD, 100 nursery/school staff who feed children with EDSD.

Aim 2 - Reviewing the evidence for interventions, outcomes measured and the tools used to measure these outcomes: Update three systematic reviews; undertake evidence mapping; investigate the outcomes and measurement tools used and preferred. Synthesise evidence.

Aim 3 – Designing trial frameworks and specification:

Twelve focus groups (six participants each, except the young people's groups which will include 3-4 participants each).

1. Two for parents of young children with physical EDSD (12 parents)
2. Two for parents of young children with non-physical EDSD (12 parents)
3. Two for professionals of young children with physical EDSD (12 professionals)
4. Two for professionals of young children with non-physical EDSD (12 professionals)
5. One to two for young people with physical EDSD (4-6 young people)
6. One to two for young people with non-physical EDSD (4-6 young people)

Delphi survey: 100-200 respondents from survey.

Two consensus workshops: 10 parents and 10 professionals at each.

Timetable:

The study will take place over 2 years. Months 1-2: Research Associate training. Start update of systematic reviews. Start mapping review. 3-4: Focus groups (parents and professionals); then survey design; engage networks. 5-7: Survey; then review properties of measurement tools. 8-10: Synthesis of evidence findings. 11-13: Focus groups about evidence findings. 14-18: Delphi survey. 19-20: Consensus workshops. 21-24: Evidence based recommendations for future trial design, completion of HTA report, dissemination.

Deliverables:

1. Identification of treatments available in the NHS for children with physical and non-physical EDSD
2. Identification of the most promising interventions and specification of the patient groups in whom the intervention(s) should be tested, including whether exemplar conditions should be used in a trial; what 'treatment as usual' comprises, and its acceptability
3. Selection of the key outcomes and recommendation of the measurement tools that could be used
4. A suggested framework and outcomes for one or more substantive pragmatic trials.

2) Background and Rationale

Eating, Drinking and Swallowing Difficulties (EDSD) may lead to inadequate calorie intake, affecting a child's nutrition, growth and general physical health (Sullivan, 2009). There are two broad causes of EDSD: 1. physical causes which can affect control of the muscles of the lips, tongue, mouth, and throat (e.g. children with cerebral palsy) and impair the efficiency and safety of sucking, chewing and swallowing; 2. non-physical causes including sensory sensitivity (leading to aversion, and potential refusal of certain foods), and rigidity or rituals associated with food or mealtimes (e.g. children with autism spectrum disorder). Physical and non-physical EDSD frequently co-exist (e.g. children with cerebral palsy or Down syndrome). Both types of difficulties make mealtimes stressful for children and their families and have negative impacts on quality of life and social participation. The interventions available for physical and non-physical EDSD are different.

Parents and carers of children with EDSD are usually supported by multidisciplinary teams of health professionals (Parr et al., 2013). Professionals identify the cause(s) of the child's EDSD by a combination of review of the child's previous and current EDSD, clinical observation, and instrumental evaluation (for example, videofluroscopy). Taking account of parents' views, individualised advice is given on how and what to feed their child to improve the safety and efficiency of eating and drinking, and how to manage behaviour so mealtimes are a positive experience (Andrew et al., 2012). It is unclear which interventions are commonly used, and whether there is robust evidence for 'best clinical practice' (Morgan et al., 2012; Marshall et al., 2015). The interventions professionals may advise families to adopt can be time consuming, can involve considerable changes to parents' usual feeding plans and are sometimes contrary to parents' beliefs about how their child should be fed. There is little evidence about which interventions are effective; which are provided in the NHS; which are viewed as acceptable and feasible by families and professionals; or how intervention success should be measured.

Trials are needed to establish the effectiveness of intervention(s) that parents can deliver at home. However, before trials can be undertaken we need to know: which groups of children are most likely to benefit; the range of interventions available; what parents and professionals think are the most relevant outcomes; what outcome measurement tools are efficient and valid; and what types of trial design would be acceptable to children, parents and professionals.

3) Aims and Objectives

This study will focus on young children with non-progressive neurodisability and an EDSD with either (or both) a physical or non-physical cause. We will conduct a scoping study regarding the question: What are the interventions, which could be delivered at home by parents, to improve eating in children with neurodisability and which are suitable for investigation in pragmatic trials?

3.1 Aims:

1. To determine which parent-delivered interventions are currently offered by NHS professionals and how parents and professionals evaluate whether an intervention is successful or not
2. To review the clinical practice and research evidence for interventions, outcomes measured and the tools used to measure these outcomes
3. To construct one or more trial frameworks acceptable to children, young people, parents and professionals; or to specify the additional evidence about interventions, outcomes and tools that would be needed to support a future trial

3.2 Objectives:

To meet Aim 1:
1.Identify the case mix of young children with physical and non-physical EDSD needing intervention, and the ages at which different interventions are used
2.Explore parents' views and experiences of the interventions received, including feasibility and acceptability, and identify which outcomes they consider more or less important
3.Obtain information from professionals about which interventions are used. Then for each intervention: Who delivers training to parents or nursery/school staff? How often is the intervention used? Where is it used? How is progress assessed and what tools are used to measure this? Do professionals think the intervention is effective and over what timescale?

To meet Aim 2:
1. Update the three high quality systematic reviews which appraise the effectiveness of interventions for EDSD
2. Conduct an evidence mapping review of interventions.
3. Identify the subgroups of children for whom there is the most robust evidence on intervention success / failure
4. Investigate the extent to which interventions have been defined and manualised to facilitate replication
5. Assess the reliability and validity of the tools, as identified in the survey and reviews, most frequently used to measure the outcomes valued by parents and professionals with regard to eating and drinking interventions in children with neurodisability

To meet Aim 3:
1. Propose the most promising candidate interventions, define 'treatment as usual', set out the key meaningful outcomes to be measured and potential measurement tools
2. Explore young person, parent and professional views on the proposed interventions, outcomes and measurement tools to be used in a future trial
3. Propose which groups of children would be included in a trial, and define inclusion/exclusion criteria
4. Specify framework(s) for one or more pragmatic trials

4) Research Plan

We describe the research plan in this section by covering:

- The health technologies being assessed
- The overall design and theory underpinning it
- The methods adopted to address each of the study's aims.
    - Aim 1: Focus groups and national survey
    - Aim 2: Systematic reviews and evidence mapping review
    - Aim 3: Further focus groups, Delphi survey and two consensus workshops

Evidence mapping review and search strategy

4.1 Health Technologies being assessed

We will identify the interventions, which could be delivered at home by parents, that are available to improve eating and drinking in children with neurodisability and are suitable for investigation in pragmatic trials. We will appraise various health technologies that may improve eating and drinking. We will not include nasogastric or gastrostomy tube feeding, as these are means to replace or supplement eating and drinking and therefore we think are outside the scope of an ‘eating and drinking interventions’ study.

4.2 Design and theoretical/conceptual framework

This proposal will use the framework of the UK Medical Research Council (MRC) guidance for ‘complex’ (multifaceted) interventions (Craig et al., 2008). Specifically, the tasks from the framework that will be addressed in the present study are: establishing evidence about the problems and solutions (here evidence about EDSD interventions and ‘treatment as usual’); and testing the procedures (here investigating the acceptability of interventions, outcomes and measures).

As recommended by the MRC framework for these stages, we will use a mixed methods approach. The study will have a sequential design where the findings of a previous step will be used to inform the following step. Thus, we will undertake focus group work and a survey; in parallel we will update three systematic reviews, followed by an evidence mapping review. Then, after evidence synthesis, further focus groups will be convened, a Delphi survey undertaken and finally two workshops to seek consensus for a proposed pragmatic trial(s).

4.2.1 Addressing Aim 1: Identifying current interventions and their evaluation

First round of focus groups

Four focus group will be conducted in the North East: one with parents of children who have physical EDSD; one with parents of children who have non-physical EDSD; one with professionals working with children with physical EDSD; one with professionals working with children who have non-physical EDSD.

Sample size:

The two parent and two professional focus groups will each include 6 participants (Kitzinger 1995) (24 participants in total).

Participants:

Parents/guardians/foster carers of children with eating and drinking difficulties will be identified from local parent organisations or research databases (for example, the Autism Spectrum Database-UK / Database of children with Autism Spectrum Disorder living in North East England (Warnell et al., 2015)). Parents will be purposively sampled to capture a wide range of eating and drinking difficulties, and diversity in family characteristics (age of child; ethnicity; rural/urban location; socioeconomic status; family size). Parr, Pennington and Morris have successfully used this method of recruitment for parent focus groups. Parents will receive a £50 shopping voucher to thank them for their time, and to cover any travel and parking costs.

Multidisciplinary team professionals working with children with EDSD will be recruited from regional professional networks in the North East (for example, the Northern Paediatric Neurodisability Network, North East hub of the Council Allied Health Professionals’ Research, the Royal College of Speech Language Therapists North East Paediatric Dysphagia Clinical Excellence Network, North East England Branch of the British Dietetic Society).

Ensuring representativeness:

We will focus on ensuring ethnic and other minority representation of participants, although participants will need to respond in English to be able to take part; we will link with relevant organisations to facilitate this.

We will offer to include and support adults with mild learning disability or poor English literacy in focus groups, where they would like to take part. We have created 'easy read' versions of our information sheets, to encourage parents/carers with low levels of literacy to take part. We have created the survey sections using plain language without compromising subsequent analysis of responses. We offer the option of a researcher providing telephone support in completion of the survey.

Procedure:

The parent advisory group will be consulted about the format and running of the focus groups and the topics to be discussed. Focus groups will aim to provide a preliminary understanding of the following topics: the range of NHS interventions offered to families of children with EDSD; who offers them and where these offers are made; the characteristics of children and their families to whom individual interventions are offered (for example, what ages the individual interventions are offered at); the dosage (frequency, duration, intensity) of individual interventions; parents' views of the acceptability of individual interventions; professionals' views of the acceptability of interventions to clinicians and to families; the facilitators and barriers to delivering individual interventions in the NHS; parents' and professionals' views of the effectiveness of individual interventions; parents' and professionals' views on how the success (and lack of success) of interventions should be measured.

Analysis:

Focus groups will be audio recorded and transcribed verbatim. The transcripts will be analysed using content analysis (Krippendorff, 2012). Researchers will familiarise themselves with the transcripts, develop and refine a coding frame from the topic guide and first two transcripts, code all four transcripts according to the coding frame, and finally map interventions, their acceptability, effectiveness and measurement. We will seek to understand the parents' and professionals' views on interventions and will undertake a proportionate analysis to address the study aims. The data will generate a preliminary overview of interventions and outcome measures currently used in the NHS, their acceptability, effectiveness.

National Survey of parents and professionals

Sample size:

We aim to survey at least: 200 parents (parents/guardians/foster carers) of children with EDSD; 100 nursery and school staff who feed children with EDSD; and 200 NHS professionals who recommend eating and drinking interventions. There will be no upper limit on the number of respondents.

Participants:

Parents will be recruited via national and regional parent networks and parent support organisations such as Special Needs Networks, Parent Carer Forums, Council for Disabled Children, Contact-a-Family, Scope, Cerebra, ASD-UK/Dasl^{n}e, National Autistic Society. We will contact Child Development Teams who reported previously they had services for children with EDSD, and ask clinicians to give out leaflets about the survey to parents of children with EDSD, and to place advertisements about the survey in waiting room areas. From previous responses to surveys advertised through the databases and networks above, we anticipate that at least 200 parents will respond within an eight week period.

Health professionals will be recruited from neurodisability and community paediatric networks in the co-applicant regions and professional bodies such as the British Academy of Childhood Disability which has a database of Child Development Teams; British Association of Community Child Health; British Society of Paediatric Gastroenterology, Hepatology and Nutrition; Royal College of Speech and Language Therapists; British Psychological Society; College of Occupational Therapy; British Dietetic Association. Advertisements will be placed in the newsletters, Facebook pages and Twitter feeds of the relevant bodies.

Nursery and school staff will be recruited via independent, academy and local authority schools in the North East, South East and South West of England. We will also contact school staff through the local education authorities, and directly, as we have for previous projects. We will focus on staff in specialist schools, but will also include staff in mainstream schools where there may be less expertise and confidence. We will also contact professionals involved in early years and childcare, through the database of Early Years providers across England, and the database of an independent specialist centre for early years children with autism.

Materials:

Advertisements about the survey will contain an online link to the survey. Contact details to request a paper copy of the questionnaires are on the advertisements for respondents who prefer them. To avoid duplication, the survey contains a statement for respondents to confirm that they have not completed the survey previously.

Procedure:

We will use the focus group data and findings from the updated systematic reviews to develop a survey of the current use of EDSD interventions across the UK and the evaluation of their success. Three parallel versions of the survey will be used: one for parents/carers of children with EDSD, one for education staff who feed children at nursery or school, and one for professionals who recommend interventions for EDSD.

The parent advisory group will advise on the draft content of the survey to finalise its content and presentation. A draft version will be piloted with three members of school staff (from local specialist and mainstream schools) and three health professionals (one speech and language therapist, one paediatrician, and one other allied health professional). Cognitive interviewing techniques will be used to check respondents' understanding of the individual questions and instructions, and the acceptability of the survey.

The survey will be open for at least 4 weeks. One reminder about the survey will be sent every two weeks via social media. Respondents will have the option to enter a prize draw to win one of five £100 shopping vouchers for each survey (Drummond et al., 2013). At the end of the survey respondents will be asked to provide their contact details if they would like to be contacted about the findings of the survey and if they would like to be included in the Delphi survey, later in the study.

Analysis:

Quantitative survey responses will be analysed using descriptive statistics. Analysis will focus on detecting differences in responses from different groups of parents and professionals – for example, by geographical region, or by physical vs non-physical EDSD. From parents' responses and those of education staff who feed children with EDSD, we will ascertain which interventions have been received, which are viewed as most effective, which are considered most acceptable, and which outcomes are deemed most important. From professionals' responses we will determine what 'treatment as usual' comprises. Specifically, we will ascertain: which interventions are most frequently offered; to whom they are offered; how they are delivered; how parents and staff are trained to use them; which outcomes are measured; and which measurement tools are used. Then regarding each intervention, we will identify: Who delivers training to parents or nursery/school staff? How frequently is the intervention used, and for how long? Where is it used? How is progress assessed and what tools are used to measure this? Do professionals think the intervention is effective and over what timescale? Thematic analysis will be used for free text responses.

Findings from the survey will be discussed by the research group, and with the parent advisory group. Summaries of findings will be created by the project team and parent advisory group and will be placed on the project webpage. Links to the page will be forwarded to all networks used to advertise the survey and all UK Child Development Teams.

4.2.2 Addressing Aim 2: Systematic Reviews, Evidence Mapping Review, Review of Measurement Properties of Tools, and Evidence Synthesis

Update of systematic reviews (including search strategy)

We will update three high quality systematic reviews on the effectiveness of interventions for EDSD in children with cerebral palsy/non-progressive neurological impairment:

- Marshall et al., 2015 (EDSD in children with autism spectrum disorder)
- Morgan et al., 2012 (interventions for EDSD in children with physical problems)
- The forthcoming National Institute for Health and Care Excellence (NICE) management of cerebral palsy guidance due to be published in January 2017 (Pennington is an advisor)

These reviews are of the effectiveness evidence base for physical and non-physical feeding interventions. Two of the reviews' authors (Marshall in Brisbane and Morgan in Melbourne) have agreed to be advisors and to collaborate with us through email and teleconference/skype.

Marshall will provide the search strategy for the ASD review. Morgan will be updating her review in 2017 and will provide the research team with access to preliminary findings. The review by NICE will be updated using the published search strategies. Updated searches will be limited to one year before the date of the last searches undertaken for the primary review, allowing for database update delays. The reviews by NICE and Morgan complement each other. Morgan's review considers interventions for children with 'neurologically based oropharyngeal dysphagia'. Studies evaluated in that review included participants with CP (2 studies) and muscular dystrophy (1 study). It is possible that the updated review will include participants with other neurological disorders (e.g. acquired brain injury) and identify CP studies included in the NICE review. The NICE guideline will review interventions specifically for children with CP but are not confining interventions to those for 'oropharyngeal dysphagia and are considering EDSD more broadly, appraising the evidence for the 'management of eating, drinking and swallowing difficulties of children and young people with cerebral palsy' (https://www.nice.org.uk/guidance/gid-cgwave0687/resources/cerebral-palsy-sc-draft-scope2). Updating the three reviews (Marshall, Morgan, NICE) will therefore ensure that all interventions with high quality evidence that are applicable to children with ASD and CP are evaluated. However, the evidence mapping review (below) will ensure we also take account of children with neurodisability not due to ASD or CP.

The methods of the primary systematic reviews will be followed. Two researchers will independently screen titles and abstracts to identify studies meeting the inclusion criteria. Full text of potentially eligible articles will be retrieved and assessed by two researchers. Data extraction will be conducted in line with that of the primary review, with particular attention to the outcomes measured and the tools used. Data will be extracted by one researcher and checked by a second reviewer. Quality assessment and synthesis will also be conducted in the same manner as the primary reviews.

Evidence mapping review and search strategy

The main purpose of the mapping review is to undertake an appropriate and proportionate approach to understanding the evidence base beyond that summarised in the updated systematic reviews.

We will specifically seek to identify interventions with lower levels of evidence than those included in the systematic reviews and information on feasibility and acceptability of interventions, outcomes and measures. The review will cover quantitative and qualitative studies. We will work with an information specialist, to augment the search strategies used in the three systematic reviews, and tailor these to individual databases in health and social care, management and information technology. Searches for the mapping review will be from 2000 onwards. Databases will include MEDLINE, MEDLINE In-Process, EMBASE, CINAHL, PsycInfo, ASSIA, SocialCare Online, The Cochrane Library (includes CDSR, DARE, CENTRAL, NHS EED), British Nursing Index, Health Business Elite. Grey literature of relevant interventions, evaluations or initiatives will be sought via Google, NHS Evidence, The Health Management Information Consortium, websites of organisations such as The Kings Fund, Nuffield Trust, Health Foundation, Social Care Institute for Excellence, NICE and relevant charitable organisations. The following trial registers will also be searched: ClinicalTrials.gov and Current Controlled Trials. In addition, experts in eating, drinking and neurodisability will be consulted for potentially relevant studies of case series.

In order to organise and categorise the literature, we will develop a descriptive framework based on a small sample of relevant studies, the three updated systematic reviews and the advice of the parent advisory group. This framework will be developed iteratively, but is expected to be based on elements such as child population (age range, physical/non-physical condition and its severity); type/purpose of intervention; study design; delivery of intervention (parents/carers/school staff/professional); outcomes measured and tools used; preferences of parents and professionals in these areas, in addition to other important characteristics of intervention or populations that are deemed relevant. Data extraction will not be exhaustive and for some of the elements no more than presence or absence will be reported. Evidence identified through the mapping review will not be quality assessed.

The mapped evidence will be summarised descriptively, and key recurring findings will be used to inform structured evidence summaries. These summaries will provide information and context for the survey, subsequent focus groups and Delphi survey, and the trial framework.

Review of outcome measurement tools

From the updates of the systematic review, the mapping review and the focus groups, the most frequently used outcome measurement tools will be identified. We will then assess their measurement properties by conducting a proportionate (rather than comprehensive) exploration of relevant literature. OVID will be searched for papers about the identified tools which describe their properties when used with children with neurodisabilities. We will also use an existing review and any relevant references in its bibliography (Benfer, Weir, & Boyd, 2012) on the clinimetric properties of measures of oropharyngeal dysphagia in cerebral palsy/neurological impairment. We will also inspect manuals of standardised tools.

Properties of the papers and of the tools will be appraised using the COSMIN checklist (Terwee et al. 2012). McConachie has training in this method. The evidence will be combined with the findings of the professional survey in order to draw conclusions about the most robust and acceptable tools for a trial(s).

4.2.3 Addressing Aim 3: Trial frameworks and specification

In order to develop trial frameworks, the evidence from the synthesis to date will be reviewed at a second round of focus groups; then consensus on trial components will be sought through a Delphi survey. Finally, following further synthesis, we will convene two national consensus workshops.

Second round of focus groups

Focus groups will include six participants each: two groups for parents of young children with physical EDSD; two for parents of young children with non-physical EDSD; two for professionals of young children with physical EDSD; two for professionals of young children with non-physical EDSD; one to two for young people with physical EDSD; one to two for young people with non-physical EDSD. Note that the young people may have communication difficulties, but we will recruit individuals of an age and ability to consent to participate and give information about the topics in the topic guide. The clinical academic researchers have extensive experience of undertaking discussion groups with young people with additional communication needs.

The four parent and four professional focus groups (48 participants in total) will be conducted in Newcastle (parents and professionals), Exeter (parents) and at Chailey Clinical Services, Sussex (professionals). The young people's groups will all take place in the North East region. Parents and young people will receive a £50 shopping voucher to thank them for their time, and also cover any travel and parking costs.

Participants:

Some of the parents and professionals who stated that they wished to be contacted about future stages of the research will be invited to the focus groups – parents will be purposively sampled from those within 30 miles of Newcastle and Exeter (where parent groups will be held). We will aim for diversity of participants in regard to their child's severity of impairment and family characteristics (including ethnicity and where they live). Groups for professionals will be multidisciplinary and a mix of genders. Professionals within 50 miles of Newcastle and Chailey will be invited to attend. Eight to twelve young people with EDSD aged 12-18 years who are known to professionals and parents around Newcastle and who are considered able to participate in small discussion groups will be identified; young person groups will take place in locations across the North East of England (Newcastle and the south of the region). Young people will be given written, verbal and pictorial information about the study and will be encouraged to discuss this with their parents or professional. If more than 12 young people wish to take part, they will be purposively selected to ensure there is mix of genders and diagnoses.

Materials:

Before the focus groups, we will ensure that young people who use augmentative and alternative communication (AAC) systems have the necessary vocabulary to discuss relevant themes. The research team will ask parents and relevant professionals to add new vocabulary items to young people's AAC systems where necessary.

Focus group participants will receive written, verbal and pictorial summaries of the findings of the survey and evidence reviews. They will be shown the candidates for future research – the interventions, valued outcomes and measurement tools. Participants will be asked for their views on the acceptability of the candidates and, if multiple candidates have been determined, their prioritisation for future investigation. Discussion in groups of young people will be facilitated by use of pictures, photographs and techniques such as Talking Mats to elicit preferences; other techniques will be necessary - we know from clinical practice and our research, that young people will use their own total communication approach in discussions.

Analysis:

Focus groups will be audio recorded and transcribed verbatim. Photographs will be taken of all Talking Mats created by young people. Analysis of the data will be based on the Framework approach (Spencer, Ritchie, & O'Connor, 2003) and will generate an understanding of the views of parents, young people and professionals on which individual interventions, outcomes and measurement tools that are supported by current research, could be tested in research, which should be prioritised (and their rationale for this) and which are inappropriate for further testing. Findings from the focus groups will be discussed by the team and our parent advisory group.

National Delphi survey

A national Delphi survey will be undertaken to seek consensus on the candidate trial components: interventions, outcomes, measurement tools and a definition of 'treatment as usual' (for comparator treatment), and to prioritise interventions for future research. Statements will be generated from the synthesis of the data from the focus groups, mapping review and updates of the systematic reviews.

Participants:

Parents and professionals who took part in the earlier survey and focus groups will be invited to take part in the Delphi survey; we aim for 100 - 200 respondents. Parents and professionals who did not take part in the earlier survey will also be invited to participate in the Delphi through the networks and organisations listed above.

Materials:

A survey will be developed to elicit parents' and professionals' judgements on the suitability of components for future trials: interventions, participant groups, outcomes, measurement tools and 'treatment as usual'. In the first phase of the Delphi survey participants will be asked to rate their agreement with statements about whether individual trial components should be included in future research (i.e. that a component is appropriate for further investigation). The second phase of the Delphi survey will aim for consensus between participants on prioritisation; for example, which interventions should be tested first in the NHS; which outcomes should be primary outcomes, and which should be secondary outcomes. We realise there may be systematic differences between parent and professional responses and these will be explored by discussions with the parent advisory group. All statements will have a rating scale on which participants indicate their agreement: for example, strongly disagree, disagree, no opinion, agree, strongly agree. The surveys used in each phase will be developed by the research team in consultation with the parent advisory group. They will be piloted with three professionals (one paediatrician, one speech and language therapist and one other allied health professional) using cognitive interviewing techniques to elicit respondents' understanding of the instructions and statements tested. We envisage at least three rounds of the survey will be needed to achieve consensus on prioritisation of trial components. The survey will be administered online using Qualtrics.

Procedure:

Advertisements for the survey will also be placed in electronic newsletters of the parent and professional groups and the Twitter feeds and Facebook pages used in Aim 1, to encourage responses and to allow people who did not take part in previous phases of the study to add their views. Participants who take part will be offered the opportunity to enter a draw to win one of five £100 shopping vouchers for each survey.

Analysis:

Consensus level for the Delphi analysis will be set at 67% (Sinha, Smyth, & Williamson, 2011); we will work with the parent advisory group on responses where there are different views between parents and professionals. Statements on which there is agreement will be identified using descriptive statistics. Thematic analysis will be used for free text responses.

Evidence Synthesis

We will generate structured evidence summaries from the updated systematic reviews, the mapping review, the surveys and the focus groups. Each summary will outline relevant aspects of the research evidence and highlight where there are evidence gaps. Content will include a description of the intervention, the population(s) to whom it may be delivered, the perceived potential target groups for the intervention, the characteristics of the published evidence to support, the level of professional and parent support. The final structure will be determined in collaboration with both the clinical and parent advisory group.

Then we will produce summaries of the elements identified as priorities in the Delphi survey. These summaries, which will form part of the evidence presented at the national consensus meetings, will show how the preferences of parents and professionals relate to the evidence base and the feasibility of delivering alternative interventions. These summaries should ensure that all elements of the work are presented in a transparent, consistent and useful format that will enable dissemination and discussion.

Two national consensus workshops regarding potential trials

Two national consensus workshops will be held in months 19-20. One workshop will be in Newcastle and one in London. One will focus on potential trials of interventions for children with physical EDSD, the other on trials for non-physical EDSD. A mix of about 20 parents, health and education professionals and people with relevant experience of neurodisability trials will be invited to the meeting. Data from the evidence synthesis, the second phase of focus groups and the Delphi survey will be summarised before the meetings, and circulated, together with some defined topics for discussion. The agenda will be set so that decisions are made in a stepwise fashion – for example, discussions about outcomes to be measured will follow discussion about the properties of the most appropriate and available measurement tools. The aim of the workshops will be to draw together all the available evidence to suggest a framework and outcomes for one or more substantive pragmatic trial(s) of interventions for children with physical and non-physical EDSD. If it is not possible to recommend a trial framework, we will consider what additional evidence about interventions, outcomes and measurement approaches is needed to support one or more future trials. The national consensus workshops are the last point of participant involvement and are planned to be finished by June 2019.

5) Dissemination and Outputs

5.1 Dissemination

We will start dissemination following Stage 1, by sending newsletters to participants and through organisations. We will create a project website.

In addition to our report to HTA and possible publication in the HTA journal, we will prepare one article for submission to a major journal in child health or child disability. We will present the findings at the British Academy of Childhood Disability annual meeting, and at the European Academy of Childhood Disability annual meeting – this focuses on conditions such as cerebral palsy, autism spectrum disorder and others. If possible we will present data at the International Meeting for Autism Research.

We will offer to present our findings at regional neurodisability meetings – parents and professionals often attend these. We will share information with clinical networks through speciality groups and Royal Colleges, and others through whom we link during the project, for example voluntary sector organisations and parent carer forums.

Parent co-investigators and members of the parent advisory group, supported by researchers, will disseminate the findings through written summaries for parent and professional participants from the project respectively, and national charities (for example the National Autistic Society, Autistica and Research Autism (Newcastle links) and Cerebra (PenCRU links); we hope parent co-applicants and members of the parent advisory group will also contribute an article to the INVOLVE newsletter. Parent co-investigators and members of the parent advisory group working with us will present the findings at parent/carer meetings wherever possible – otherwise another co-applicant will attend.

Our previous research experience tells us that different groups within the community prefer different formats and dissemination routes (for example, many adults on the autism spectrum prefer social media, many older parents prefer paper, younger people make more use of web based approaches). We will aim to accommodate the preferences of all audiences and tailor dissemination formats, methods and content for the people to whom it is directed. We will provide feedback findings to end-users following each research stage to build and maintain engagement.

We will use printed materials, email and social media for dissemination, as well as webinars and YouTube videos that can be distributed on line or through Facebook or Twitter.

Finally, we will share our findings with research partners in other countries, to ensure best use of the results (for example, colleagues in Australia).

5.2 Outputs

These will include: Identification of the most promising interventions for young children with physical and non-physical EDSD; specification of the patient groups on whom the intervention(s) should be tested, and whether one or more exemplar conditions should be considered for a trial; what 'treatment as usual' should comprise in a future trial, and its acceptability; selection of the key outcomes to be measured; recommendation of the tools that could be used. Identification of a suggested framework and outcomes for one or more substantive pragmatic trial(s); or if it is not possible to recommend a trial framework, we will set out what additional evidence about interventions, outcomes and measurement approaches is needed to justify a trial.

6) Study management

Parr will have overall responsibility for the project, and will complete progress reports and financial reporting to NIHR, the Sponsor and ethics committee. Parr and Pennington will lead day to day working.

Co-applicants will speak together at least 3 monthly during the project (in-person meetings or via teleconference). A multidisciplinary National Advisory Group will be recruited. This group will have a wide geographical distribution and include researchers and professionals with experience in Paediatric Neurodisability including Paediatricians, Speech and Language Therapists and other allied health professionals or Clinical Psychologists. The group will comprise of 4-6 people and will meet up to 4 times during the study,

Newcastle upon Tyne Hospitals NHS Foundation Trust is the research sponsor and lead NHS Trust.

7) Patient and Public Involvement

A parent advisory group will meet 6-8 times to discuss specific topics – including those arising from recent stages and findings, and to prepare for the next phase. Specific examples of the purpose of the 2 hour parent advisory meetings include (but are not limited to) the following: Initial advice on methods and materials, including how to best conduct Stage 1 focus groups; review survey information sheet and consent forms; assist review of the results from the evidence synthesis and prepare for Stage 2 focus groups, including the discussion with young people; consider the Delphi survey content; prepare for the consensus workshops; a final meeting to guide dissemination of the results to parents and young people.
One of two parent co-investigators will lead the parent advisory groups, together with researchers. A parent co-applicant will attend Newcastle parent groups, and will lead parent involvement for the consensus meetings. With Parr, parent co-investigators will lead dissemination of the project results to parents through networks and voluntary sector organisations.

8) Research team

Newcastle University / Newcastle upon Tyne Hospitals NHS Foundation Trust

Parr is a Clinical Senior Lecturer and Consultant in Paediatric Neurodisability, and leads a Tertiary neurodisability feeding service.
Pennington is a Senior Lecturer in Speech and Language Therapy.
Craig is a Principal Scientist with expertise in evidence synthesis.
Colver is Professor of Community Child Health.
McConachie is Professor of Child Clinical Psychology.
McColl previously directed the Newcastle Clinical Trials Unit.
Thomas is a Consultant Gastroenterologist
Buswell is a Speech and Language Therapist
Cadwgan is a Consultant in Paediatric Neurodisability (now based at Guy's and St Thomas' Hospital
Taylor is the Clinical Research Associate on the study

Two parent co-investigators work as part of the research team – one is a parent of a young person with physical disability, and the other is a parent of a young person on the autism spectrum

University of Exeter Peninsula Cerebra Research Unit (PenCRU)
Morris is a Senior Health Service Researcher and leads PenCRU.

Chailey Clinical Services, Sussex
Sellers is a clinical and academic Speech and Language Therapist.

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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

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ABSTRACT

Background

Young children with neurodisability commonly experience eating, drinking and swallowing difficulties (EDSD). Little is documented about which interventions and outcomes are most appropriate for such children. We aimed to seek consensus between parents of children with neurodisability and health professionals on the appropriate interventions and outcomes to inform future clinical developments and research studies.

Methods

Two populations were sampled: parents of children aged up to 12 years with neurodisability who experienced EDSD; health professionals working with children and young people (aged 0-18 years) with neurodisability with experience of EDSD. Participants had taken part in a previous national survey and were invited to take part in a Delphi survey and / or consultation workshops. Two rounds of this Delphi survey sought agreement on the appropriate interventions and outcomes for use with children with neurodisability and EDSD. Two stakeholder consultation workshops were iterative, with the findings of the first discussed at the second, and conclusions reached.

Results

A total of 105 parents and 105 health professionals took part. Parents and health professionals viewed 19 interventions and 10 outcomes as essential. Interventions related to improvement in the physical aspects of a child's EDSD, behavioural changes of the child or parent, and changes in the child or family's well-being. Both parents and health professionals supported a 'toolkit' of interventions that they could use together in shared decision making to prioritise and implement timely interventions appropriate to the child.

Conclusions

This study identified interventions viewed as essential to consider for improving EDSD in children with neurodisability. It also identified several key

outcomes that are valued by parents and health professionals. The FEEDS Toolkit of interventions to improve EDSD in children with neurodisability has been developed and now requires evaluation regarding its use and effectiveness.

What is known about the subject?

- Children with neurodisability commonly experience eating, drinking and swallowing difficulties (EDSD) that have physical and non-physical causes.
- EDSD have a considerable impact on a child and family.
- A UK survey found a wide range of parent-delivered interventions are recommended by health professionals and used by parents to support young children with neurodisability.

What this study adds?

- Agreement from parents and health professionals on the appropriate interventions and outcomes for use with children with neurodisability and EDSD.
- Clarity on the interventions and outcomes to focus on within future research
- A toolkit of interventions was developed for use by health professionals and parents to support children with neurodisability and EDSD.

INTRODUCTION

Long-term conditions affecting the brain, nerves and muscles are often grouped under the term ‘neurodisability’ [1]. Children with neurodisability commonly experience eating, drinking and swallowing difficulties (EDSD) that have physical and non-physical causes. Physical causes relate to decreased muscle control and co-ordination, which impairs the safety and efficiency of sucking, chewing and swallowing. 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). Physical and non-physical EDSD frequently co-exist (mixed EDSD). EDSD make mealtimes stressful for children and their families and impact negatively on quality of life and social participation. They also lead to inadequate calorie intake or a restricted diet, affecting a child’s nutrition, growth and physical health [2].

A recent UK survey of parents and health professionals found a wide range of interventions were used for children with neurodisability who experience EDSD to address their physiological and behavioural needs [3]. The survey found most children received multiple interventions. There was a common approach to addressing EDSD regardless of the cause of the child's difficulties, with the majority of interventions being used to address all types of EDSD. This survey also identified a range of important outcomes to measure the effectiveness of interventions.

As part of a larger research programme, FEEDS (Focus on Early Eating, Drinking and Swallowing) [4], this study aimed to:

1. Seek consensus between parents and health professionals on which interventions and outcomes are most appropriate for children with neurodisability and EDSD.

2. Gain consensus between parents of children with neurodisability and health professionals on which interventions should be evaluated in future research.

3. Develop a 'toolkit' of interventions that could be used by health professionals and parents to support children with EDSD and their families.

METHODS

An iterative online Delphi survey and two stakeholder consultation workshops were undertaken.

Delphi survey

Participants

Invitations to participate were sent to respondents from the FEEDS national survey [3] who had expressed interest in subsequent research stages. This included: parents of children (aged up to 12 years) with neurodisability who experienced EDSD; and health professionals working with children and young people (aged 0-18 years) with neurodisability. Participants were recruited through a wide range of sources, including NHS, professional and parent networks and schools. Full recruitment strategies are outlined elsewhere [4]

Measure

The questionnaire listed interventions and outcomes identified in earlier stages of the FEEDS research programme [4], comprising updates of three systematic reviews [5-7], a mapping review, a national survey and focus groups. The questionnaire's structure and format was developed with reference to methodological recommendations [8] and previous experience of Delphi surveys. The questionnaire contained three sections [1] demographic characteristics; [2] parent-delivered interventions for young children with neurodisability and EDSD; and [3] outcomes to measure improvement in EDSD.

Questions related to 25 interventions and 22 outcomes (Tables 1 and 2). Respondents rated the importance of the interventions as part of a treatment package for EDSD, and the outcomes to measure (using a 9-point scale: 0-3 'not important', 4-6 'important but not essential', 7-9 'essential'). Respondents could tick "unable to score". The questionnaire was hosted on Qualtrics [9].

Table 1. Description of interventions presented in Delphi Survey

Intervention	Description
Modifying environment	Changing the physical or social setting at mealtimes (e.g. reducing distractions such as levels of noise; using distractions to reduce a child's attention on their food
Positioning	Ensuring a child is in the best position to eat and drink food safely and efficiently (e.g. a child sitting upright providing support for head control)
Modifying equipment	Using different spoons, forks, plates, cups, or bottles (e.g. doidy cup; plastic spoon)
Scheduling of meals	Setting the timing of mealtimes to encourage a child's appetite and establish a mealtime routine (e.g. spreading meals / snacks throughout the day; setting a 30 minutes limit for mealtimes)
Modifying consistency of food	Changing the consistency of the child's food or drink (e.g. pureeing food; thickening food or drink)
Modifying other aspects of food	Changing the temperature, taste, amount or presentation of the child's food or drink (e.g. presenting different foods so they do not touch each other; mixing liked foods with disliked foods)
Modifying placement of food	Changing where food is placed in a child's mouth to help chewing or swallowing (e.g. placing food to the side of the mouth)
Enhancing communication	Improving communication between a child and the person feeding them during mealtimes (e.g. offering choices of food to a child; a child using eye pointing or signs or symbols to ask for specific food or drink)
Visual supports	Use of pictures, a 'countdown clock', or social stories to increase a child's understanding of what happens during mealtimes (e.g. showing a child pictures of what food will be on their plate; showing a child a story to explain what will happen during a mealtime)
Responding to a child's cues for feeding	Helping people to recognise the signs that a child is ready to take another mouthful of food or drink (e.g. looking for breath alterations or repeated swallows from a child to indicate a lack of readiness)
Pace of feeding	Changing the speed at which each mouthful of food or drink is taken by a child (e.g. slowing pace down to prevent overfilling of a child's mouth)
Medication	Any medication (e.g. for epilepsy, pain, drooling, tone, gastroesophageal reflux)
Energy supplements	Any energy or calorie supplement given orally or via feeding tube

Vitamin or nutritional supplements	Any supplements given or changes to a child’s diet to increase the vitamins or nutrients in their diet
Physical support	Giving direct physical support to a child when eating or drinking to improve the movements needed to bite, chew and swallow (e.g. placing a thumb underneath the chin to help a child close their mouth)
Oral and sensory desensitisation	Activities aimed at reducing a child’s adverse reactions to different sensory experiences linked to eating and drinking (e.g. face massage; chewing no-food items such as a chewy ‘toothbrush’)
Oral-motor exercises	Exercises done with a child to improve the control of their mouth, jaw, tongue or lips (e.g. a child moving a non-food item with their tongue; a child sucking through a straw)
Graded exposure to new food	Activities aimed at gradually exposing a child to new or disliked foods and drinks (e.g. messy play activities involving a child touching new or disliked foods; using small steps towards a child accepting new or disliked foods such as licking the food or putting it in their mouth with no expectation to swallow)
Graded exposure to new textures	Activities aimed at gradually introducing a child to more challenging food textures and fluid consistencies (e.g. messy play activities involving a child touching new or disliked textures; using small steps to introduce a child to lumpy food or foods that require chewing)
Changing behaviour at mealtimes	Strategies to encourage a child to behave appropriately at mealtimes (e.g. a child sitting down ready to eat; a child staying seated for the meal)
Modelling	Giving a child the opportunity to learn from others by eating and drinking with them (e.g. sitting a child with other children or family members at mealtimes)
Training to self-feed	Teaching a child to feed themselves (e.g. placing a hand over a child’s hand to help guide the food into their mouth)
Support for parents	Help for parents around their child’s eating and drinking difficulties (e.g. counselling; parent support groups)
Sharing information	Any information shared to help parents and professional understand a child’s difficulties with eating and drinking (e.g. professionals teaching parents and school staff about a child’s physical or sensory difficulties; parents helping professionals understand what’s important about mealtimes in their family)
Psychological support for children	Psychological help for a child (e.g. counselling)

Table 2. Description of outcomes presented in Delphi Survey

Outcome	Description
General health	A child's overall health
Weight	How much a child weighs
Height	How tall a child is
Growth	A change in a child's growth, including height and weight
Nutrition	A child's level of energy and nutrients for healthy growth
Child's enjoyment of mealtimes	
Parent or caregiver's enjoyment of mealtimes	
Quality of life of child	How satisfied a child feels about their life
Quality of life of family	How satisfied other family members feel about their (own) lives
Mental health of parent or caregiver	A parent / caregiver's mood and emotional wellbeing
Safety	A child's ability to eat and drink safely without choking or aspirating
Oral motor control	A child's ability to control the movement of their mouth, jaw, tongue or lips and swallow
Efficiency	A child's ability to eat and drink at a reasonable pace
Independence	A child's ability to feed themselves
Variety	The range of foods or liquids a child eats or drinks
Amount	The amount of food or liquid a child eats or drinks per day
Appetite	A child's level of hunger and desire for food / drink
Mealtime behaviour	A child behaving appropriately during meals
Mealtime interaction	The interaction between a child and the person feeding them at mealtimes
Social participation	A child's overall involvement at mealtimes
Child's understanding	A child's understanding of mealtime activities and routines
Parent or caregiver's understanding	A parent / caregiver's insight into their child's eating and drinking difficulties

Patient and public involvement

The questionnaire and information sheet were developed by the research team, which included parent co-investigators, in consultation with the Parent Advisory Group (PAG) and following focus groups with parents and health professionals [4].

Procedure

The same questionnaire was sent to parents and health professionals in two rounds. In round one, respondents rated the importance of individual intervention categories, and outcomes. In round two, respondents were shown bar charts of parent and health professionals' ratings from round one and then re-rated the importance of each intervention and outcome. No items were removed between rounds. Both survey rounds were open for three weeks with a week between the rounds for data analysis. Respondents and non-respondents from round one were invited to take part in round two, to maximise participation. Round two respondents entered a prize draw to win one of five £100 vouchers for each stakeholder group.

Analysis

Consensus was conservatively defined as ≥ 67% and required each stakeholder group to rate an intervention or outcome as essential (rated 7-9 at round two) [8].

Stakeholder workshops

Participants

Parents who took part in the FEEDS national survey [3] and had expressed interest in subsequent research stages were invited to participate. Participants had to be able to travel to North East and South East England for the workshops. Invitations were sent to health professionals linked to regional and national clinical networks. Participants were purposively selected to maximise variation in their experience of EDSD and service provision.

Design

Two half-day workshops were held (Newcastle upon Tyne and London). The workshops aimed to facilitate detailed discussion on (1) Which interventions and outcomes should be evaluated in future research?; (2) A proposed intervention 'toolkit' for EDSD (developed during previous study stages), including: How could the essential interventions identified in the Delphi survey be presented to parents as a list of treatment options?; What level of detail would parents need on each intervention?; How would a menu of treatment options be individualised?; What level of support would families need from health professionals to use the toolkit?

Patient and public involvement

Parent co-investigators were involved in the design and delivery of the workshops. The PAG also reviewed workshop materials and commented on the structure and timings of tasks.

Procedure

Attendees were presented with a study overview including the main findings from earlier research stages. Individual topics were discussed in small mixed groups of parents and professionals. One research team member facilitated each group and notes were taken. The workshops were iterative, with the results of the first workshop being presented at the second. To thank them for their time and/or cover travel costs, parents and professionals received a shopping voucher.

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 [4].

RESULTS

Delphi survey

196 parents and 175 health professionals were invited (see Figure 1). 81 parents (41%) and 61 parents (31%) responded to rounds one and two respectively, with 52 parents responding to both rounds. 76 health professionals (43%) and 61 health professionals (35%) responded to rounds one and two respectively, with 51 health professionals responding to both rounds.

[Insert figure 1 about here]

Participant Characteristics

The characteristics of respondents are shown in Table 3. Similar proportions of parents and health professionals participated in round one (49% and 51% respectively), and round two (50% and 50% respectively). The characteristics of respondents who completed both rounds and those who completed round two only were very similar. See Supplementary Tables 1 and 2 for full details of respondents and non-respondents.

Table 3. Characteristics of Delphi Survey respondents for Rounds 1 and 2

	Round 1 N=158		Round 2 N=123	
	Parents N=81 n (%)	HPs N=76 n (%)	Parents N=61 n (%)	HPs N=61 n (%)
Age[a]				
Under 20 years	0 (0)	0 (0)	0 (0)	0 (0)
21-30 years	2 (3)	8 (11)	2 (3)	3 (5)
31-40 years	32 (40)	19 (25)	23 (38)	17 (28)
41-50 years	40 (49)	25 (33)	32 (53)	20 (33)
51-60 years	7 (9)	22 (29)	4 (7)	20 (33)
61 years and over	0 (0)	2 (3)	0 (0)	1 (2)
Gender[a]				

Female	76 (94)	71 (93)	58 (95)	58 (95)
Male	5 (6)	4 (5)	3 (5)	3 (5)
Prefer not to say	0 (0)	1 (1)	0 (0)	0 (0)
Location				
England				
North East	14 (17)	5 (7)	11 (18)	7 (12)
North West	8 (10)	3 (4)	6 (10)	3 (5)
Yorkshire and Humber	5 (6)	10 (13)	2 (3)	9 (15)
Midlands	11 (14)	16 (21)	9 (14)	10 (16)
South East including London	27 (33)	26 (34)	20 (33)	21 (34)
South West	8 (10)	8 (11)	7 (12)	4 (7)
Scotland	3 (4)	4 (5)	2 (3)	5 (8)
Northern Ireland	2 (3)	0 (0)	2 (3)	0 (0)
Wales	1 (1)	4 (5)	1 (2)	2 (3)
Missing	2 (3)	0 (0)	1 (2)	0 (0)
Ethnicity[a]				
White	78 (96)	70 (92)	59 (97)	55 (90)
Asian / Asian British	2 (3)	3 (4)	0 (0)	4 (7)
Black / African / Caribbean / Black British	0 (0)	0 (0)	1 (2)	0 (0)
Mixed / Multiple ethnic group	1 (1)	1 (1)	1 (2)	1 (2)
Other ethnic group	0 (0)	2 (3)	0 (0)	1 (2)
Prefer not to say	0 (0)	0 (0)	0 (0)	0 (0)
Nature of child's EDSD				
Physical EDSD	14 (17)	14 (18)	9 (15)	13 (21)
Nonphysical EDSD	40 (49)	5 (7)	32 (53)	3 (5)
Mixed EDSD	27 (33)	57 (75)	20 (33)	45 (74)
Missing	0 (0)	0 (0)	0 (0)	0 (0)

[a] No missing data

Interventions for children with neurodisability and EDSD

Table 4 shows the proportion of parents and health professionals who rated interventions as essential in rounds one and two. Consensus was achieved for 17/25 interventions at round one, increasing to 19/25 interventions at round two. The interventions rated as an essential part of an intervention package for young children with neurodisability and EDSD are shown in Table 4. See Supplementary Tables 3 and 4 for all intervention ratings.

Table 4. Parents' and health professionals' rating of interventions as essential on Round 1 and 2 of the Delphi Survey

Bold denotes a rating of 'essential' (score 7-9) by ≥ 67% within the stakeholder group. Shaded cell denotes agreement by both stakeholder groups that the item was 'essential' (score 7-9) ≥ 67%.

	Round 1	Round 2

Intervention	Parents N = 81 %	Health professionals N = 76 %	Parents N = 61 %	Health professionals N = 61 %
Modifying environment	**67**	**87**	**77**	**95**
Positioning	**92**	**97**	**96**	**100**
Modifying equipment	**76**	**87**	**93**	**90**
Scheduling of meals	53	**82**	50	**83**
Modifying consistency of food or drink	**79**	**86**	**79**	**96**
Modifying other aspects of food or drink	**74**	**75**	**86**	**83**
Modifying placement of food	**68**	**79**	**75**	**90**
Enhancing communication	**76**	**82**	**86**	**90**
Visual supports	52	63	52	**72**
Responding to a child's cues for feeding	**83**	**94**	**93**	**96**
Pace of feeding	**77**	**96**	**89**	**100**
Physical support	**72**	**69**	**82**	**81**
Oral and sensory desensitisation	**72**	**68**	**82**	**75**
Oral-motor exercises	**73**	40	**70**	35
Graded exposure to new food	66	**85**	**70**	**84**
Graded exposure to new textures	**68**	**81**	**76**	**81**
Changing behaviour at mealtimes	57	63	58	56
Modelling	**80**	**82**	**77**	**83**
Training to self-feed	**68**	47	55	46
Support for parents	**81**	**84**	**95**	**96**
Psychological support for child	**72**	63	**77**	59
Medication	**78**	**86**	**87**	**91**
Energy supplements	62	**74**	**69**	**73**
Sharing information	**90**	**95**	**100**	**97**
Vitamin or nutritional supplements	**68**	**68**	**85**	**75**

Outcomes for children with neurodisability and EDSD

Table 5 shows the proportions of parents and health professionals who rated outcomes as essential in rounds one and two. The outcomes for which there was consensus on did not change between rounds. 10 outcomes were viewed as essential; some related to physical health, such as safety and growth, and others to the International Classification of Functioning Disability and Health, such as child social participation. See Supplementary Tables 5 and 6 for all outcome ratings.

Table 5. Parents' and health professionals' agreement on outcomes rated as essential on Round 1 and Round 2 of the Delphi Survey

Bold denotes a rating of 'essential' (score 7-9) by ≥ 67% within the stakeholder group. Shaded cell denotes agreement by both stakeholder groups that the item was 'essential' (score 7-9) ≥ 67%.

Outcome	Round 1 Parents N = 81	Round 1 Health professionals N=76	Round 2 Parents N=61	Round 2 Health professionals N=61
Nutrition	**89**	**97**	**95**	**98**
General Health	**89**	**93**	**97**	**98**
Weight	53	51	34	48
Height	31	32	12	12
Growth	**75**	**76**	**82**	**89**
Child's enjoyment of mealtimes	**83**	**91**	**90**	**98**
Parent's enjoyment of mealtimes	42	**76**	39	**78**
Quality of life of child	**95**	**92**	**98**	**100**
Quality of life of family	**78**	**87**	**90**	**97**
Mental health of parent	**83**	**84**	**93**	**97**
Safety	**97**	**97**	**100**	**100**
Oral-motor control	**87**	**74**	**86**	**72**
Efficiency	44	60	17	46
Independence	60	31	43	28
Variety	51	23	26	12
Amount	62	40	53	25
Appetite	59	44	46	38
Mealtime behaviour	41	30	34	26
Mealtime Interaction	61	**81**	65	**79**
Social participation	50	**77**	53	**74**
Parent's understanding of child's EDSD	**89**	**89**	**95**	**93**
Child's understanding of mealtimes	51	51	58	40

Stakeholder Workshops

15 parents and 19 health professionals took part in the workshops.

Participant Characteristics

Nine parents had children with physical EDSD, two had children with non-physical EDSD, two had children with mixed EDSD, and two had one child with physical EDSD and one child with non-physical EDSD. Health professionals comprised six speech and language therapists, four dietitians, four paediatricians, three occupational therapists, two clinical psychologists, a physiotherapist, and a nurse.

Interventions and outcomes for evaluation in future research

Parents and health professionals agreed that no single intervention was suitable for all children with EDSD as many children require a number of interventions concurrently or sequentially. Both parents and health professionals endorsed the idea of an intervention 'toolkit' that could be used together to identify the most appropriate interventions for individual children and their families. They thought the toolkit should be visually represented and be available as a digital and hard copy with interactive properties to support communication between parents and professionals. They emphasised the need for flexibility in the toolkit to allow families and health professionals to select the most appropriate interventions, at the right time. Some parents thought they would want to be able to see the whole toolkit, to facilitate a central parental role in intervention prioritisation. Parents and health professionals thought that detailed information was needed for each intervention to fully inform families and allow them to share in decision-making.

Paricipants thought a lead health professional (such as a speech and language therapist) and multidisciplinary team should support families in their toolkit use. The nature of support needed would vary between families and may include psychological input. Parents and health professionals raised a number of practical issues about toolkit use, including: how to deliver the toolkit to meet the needs of a heterogeneous population with diverse EDSD; how to deliver the toolkit where multidisciplinary EDSD team professionals are unavailable or under-resourced; and how to deliver the toolkit to children with non-physical EDSD who may not currently receive multidisciplinary team healthcare.

Toolkit of interventions for children with neurodisability and EDSD

Using the findings from the Delphi survey and workshops, alongside findings from other stages of the FEEDS research programme [4], we developed the FEEDS Toolkit of interventions for use by health professionals and parents to support children with neurodisability and EDSD (see Figure 2). The FEEDS Toolkit comprises 19 EDSD interventions: 15 for use with children with all types of EDSD, two for use with children with physical or mixed EDSD only and two that are rarely offered by the UK NHS (oral motor excercises and psychological support for the child). The FEEDS Toolkit also includes ongoing interventions that influence EDSD strategies such as individual context, medical issues and sharing information.

[Insert figure 2 about here]

DISCUSSION

The Delphi survey established consensus on the 19 essential interventions to include in the FEEDS Toolkit, and 10 outcomes of importance. The stakeholder workshops showed support from parents and health professionals for the FEEDS Toolkit that could be worked through by health professionals and parents. Rather than evaluating single standalone interventions, we suggest that future research should evaluate a combination of interventions within the FEEDS Toolkit.

The large number and diversity of interventions identified as essential for inclusion in the toolkit reflects the heterogeneity of children with neurodisability and EDSD, and their families. Beresford et al [10] found health professionals working with children with neurodisability had a “great big menu of interventions to choose from” which were highly individualised. Health professionals talked about taking an eclectic approach and using a range of interventions from their toolbox with children with neurodisability and their families; key factors affecting decision making regarding appropriate interventions included child and family’s characteristics and resources [10]. McAnuff et al [11] described a prototype for an interactive toolkit to support families and health professionals to identify opportunities for change, and to jointly select appropriate interventions. This is in keeping with views regarding how the FEEDS toolkit might be operationalised.

[illegible]

Strengths and limitations

We acknowledge the potential risks of sampling and response bias. Participants from the FEEDS national survey were recruited from wide ranging sources [4]; their data allowed comparison of the characteristics of Delphi survey respondents and non-respondents. The overall response (≈40%) was acceptable. There was minimal difference between the characteristics of respondents between rounds one and two Through contacting non-respondents from round one in round two we increased round two responses thereby improving precision. We used a conservative consensus definition of ≥67%; our findings may have differed if we had used different consensus definitions.

The workshops had representation from two diverse geographical areas and parents and professionals with a broad range of EDSD experiences. The iterative nature of the workshops facilitated detailed discussions. Young people with EDSD were not invited to the workshops; however, at separate young people's focus groups, they agreed the importance of the outcomes identified [4].

Conclusions

The FEEDS Delphi survey and workshops identified the interventions essential to consider for improving EDSD in children with neurodisability. They also identified the most important outcomes to measure, focusing on both the child and the wider family. These findings, alongside findings from earlier stages of the FEEDS research programme [4] have been used to develop a toolkit of interventions. The FEEDS Toolkit requires evaluation of its feasibility and acceptability, and its effectiveness for improving outcomes for children and families.

Contributors: JP was Chief Investigator, co-led the design and delivery of the study, supervised the Delphi survey data analysis, co-led the consultation workshops and analysed the data. LP co-led the design and delivery of the project, co-led the consultation workshops and analysed the data. HT developed the Delphi survey materials, ran the Delphi survey and analysed the data, and co-led the consultation workshops. CM, JC, DS, JS, DG, JT and EM contributed to the design of the Delphi survey. CB, AC, DG, CM, HM, JS, JT, JC and DS co-facilitated the consultation workshops. All authors contributed to the study design, interpretation of results, writing of the manuscript, and reviewed and approved the final version.

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The NIHR HTA report from the research (including that reported in this manuscript) can be found at: https://www.journalslibrary.nihr.ac.uk/hta/hta25220/#/full-report

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Patient consent for publication: Not required

Ethics approval: This study was approved by The West Midlands and the Black Country Research Ethics Committee (17/WM/0439). Completion of the Delphi survey was taken as informed consent and informed consent was taken at the start of the stakeholder workshops.

Data availability statement: Data that support the findings of this study are available on request from the corresponding author [JP].

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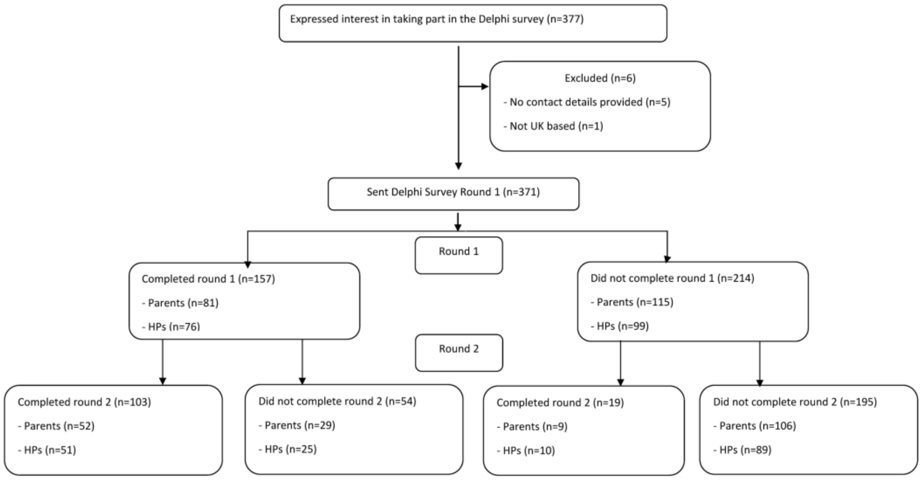
Figure 1. Flow diagram of Delphi Survey recruitment



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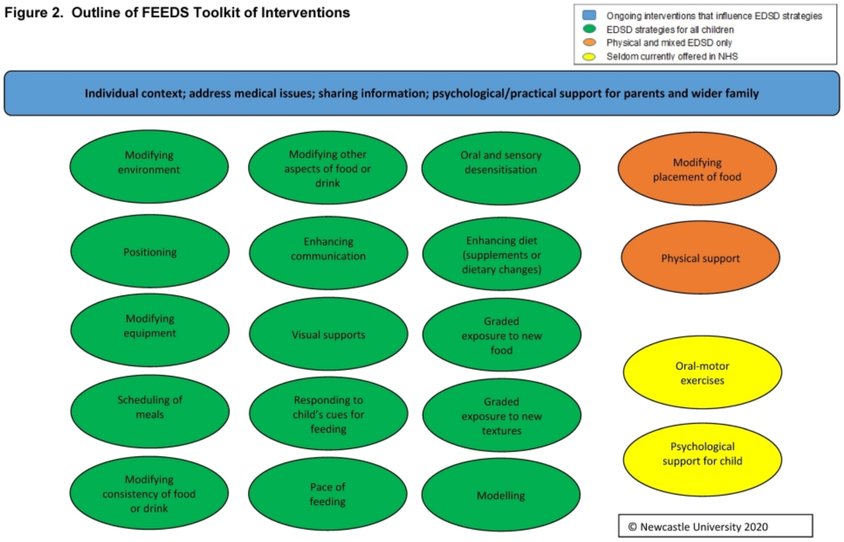

Figure 2. Outline of FEEDS Toolkit of Interventions

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Supplementary Table 1. Characteristics of respondents who completed both rounds of Delphi Survey and those who only completed Round 2

	Round 1 and 2 N=103	**Round 2 only N=19**
Role		
Parent	52 (51) [c]	9 (47)
Health Professional	51 (50) [c]	10 (53)
Age		
Under 20 years	0 (0)	0 (0)
21-30 years	5 (5)	0 (0)
31-40 years	28 (27)	12 (63)
41-50 years	47 (46)	5 (26)
51-60 years	22 (21)	2 (11)
61-70 years	0 (0)	0 (0)
Over 70 years	1 (1)	0 (0)
Missing	0 (0)	0 (0)
Gender		
Female	98 (95)	18 (95)
Male	5 (5)	1 (5)
Prefer not to say	0 (0)	0 (0)
Missing	0 (0)	0 (0)
Location		
England		
North East	15 (15)	3 (16)
North West	8 (8)	1 (5)
Yorkshire and Humber	9 (9)	2 (11)
Midlands	15 (15)	4 (21)
South East including London	35 (34)	6 (32)
South West England	10 (10)	1 (5)
Scotland	5 (5)	2 (11)
Northern Ireland	2 (2)	0 (0)
Wales	3 (3)	0 (0)
Missing	1 (1)	0 (0)
Ethnicity		
White	98 (95)	16 (84)
Black / African / Caribbean / Black British	0 (0)	1 (5)
Asian / Asian British	3 (3)	1 (5)
Mixed / Multiple ethnic group	2 (2)	0 (0)
Other ethnic group	0 (0)	1 (5)
Prefer not to say	0 (0)	0 (0)
Missing	0 (0)	0 (0)
Type of EDSD of child[a]		
Physical EDSD	21 (20)	1 (5)
Non-physical EDSD	28 (27)	7 (37)
Mixed EDSD [b]	54 (52)	11 (58)
Missing	0 (0)	0 (0)

[a] EDSD refers to eating, drinking and swallowing difficulties. [b] Mixed EDSD refers to children with physical and non-physical causes to their EDSD. [c] Percentages add up to more than 100% as a result of rounding the number to the nearest whole number.

Supplementary Table 2. Characteristics of non-respondents to the Delphi Survey

	Non-respondents N=195	
	Parents N=269 n (%)	HPs N=335 n (%)
Age (no missing data)		
Under 20 years	5 (2)	- [a]
21-30 years	23 (9)	- [a]
31-40 years	130 (48)	- [a]
41-50 years	95 (35)	- [a]
51-60 years	14 (5)	- [a]
61 years and over	2 (1)	- [a]
Gender (no missing data)		
Female	254 (94)	- [a]
Male	15 (6)	- [a]
Prefer not to say	0 (0)	- [a]
Location		
England		
North East	48 (18)	29 (9)
North West	20 (7)	22 (7)
Yorkshire and Humber	28 (10)	49 (15)
Midlands	66 (25)	47 (14)
South East including London	56 (21)	136 (41)
South West	29 (11)	14 (4)
Scotland	11 (4)	14 (4)
Northern Ireland	4 (2)	11 (3)
Wales	7 (3)	13 (4)
Missing	0 (0)	0 (0)
Ethnicity (no missing data)		
White	234 (87)	- [a]
Asian / Asian British	22 (8)	- [a]
Black / African / Caribbean / Black British	4 (2)	- [a]
Mixed / Multiple ethnic group	7 (3)	- [a]
Other ethnic group	0 (0)	- [a]
Prefer not to say	2 (1)	- [a]
Nature of child's EDSD		
Physical EDSD	58 (22)	63 (19)
Nonphysical EDSD	141 (52)	23 (7)
Mixed EDSD	59 (22)	248 (74)
Missing	11 (4)	0 (0)

[a] Data not collected in national survey.

Supplementary Table 3. Parents' and health professionals' ratings of interventions on Round 1 of the Delphi Survey

	n	Not Important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %	n	Not important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %
Modifying environment	78	3	31	**67**	74	0	14	**87**
Positioning	72	1	7	**92**	74	0	3	**97**
Modifying equipment	75	7	17	**76**	74	0	14	**87**
Scheduling of meals	79	13	34	53	74	0	18	**82**
Modifying consistency of food or drink	70	9	13	**79**	72	1	13	**86**
Modifying other aspects of food or drink	76	5	21	**74**	73	3	22	**75**
Modifying placement of food	60	10	22	**68**	70	3	19	**79**
Enhancing communication	75	4	20	**76**	73	0	18	**82**
Visual supports	71	11	37	52	71	0	37	63
Responding to a child's cues	64	5	13	**83**	71	1	4	**94**
Pace of feeding	70	1	21	**77**	71	0	4	**96**
Physical supports	54	13	15	**72**	67	3	28	**69**
Medication	49	8	14	**78**	70	0	14	**86**
Energy supplements	45	13	24	62	68	0	27	**74**
Vitamin or nutritional supplements	60	7	25	**68**	68	0	32	**68**
Oral and sensory desensitisation	68	6	20	**72**	72	10	22	**68**
Oral-motor exercises	59	7	20	**73**	68	27	34	40
Graded exposure to new food	73	6	29	66	72	0	15	**85**
Graded exposure to new textures	75	3	29	**68**	73	0	19	**81**
Changing behaviour at mealtimes	76	7	37	57	73	4	33	63
Modelling	79	3	18	**80**	73	0	18	**82**
Training to self-feed	69	6	26	**68**	72	4	49	47
Support for parents	74	3	16	**81**	73	0	16	**84**
Sharing information	76	0	11	**90**	73	0	6	**95**
Psychological support for child	65	9	19	**72**	70	3	34	63

The above figures are for those respondents who were able to score individual interventions (i.e. those who had used them) and therefore do not include those who reported being unable to score or for whom data was missing. Percentages were rounded to the nearest whole number and therefore rounded totals are occasionally different to 100%. Scores above the consensus rating of ≥67% are shown in bold.

Supplementary Table 4. Parents' and health professionals' ratings of interventions on Round 2 of the Delphi Survey

Intervention	Parents N=61				Health professionals N=61			
	n	Not Important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %	n	Not important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %
Modifying environment	60	2	22	**77**	57	0	5	**95**
Positioning	54	2	2	**96**	57	0	0	**100**
Modifying equipment	54	4	4	**93**	57	0	11	**90**
Scheduling of meals	58	5	45	50	57	0	18	**83**
Modifying consistency of food or drink	56	2	20	**79**	54	0	4	**96**
Modifying other aspects of food or drink	59	3	10	**86**	57	2	16	**83**
Modifying placement of food	48	2	23	**75**	57	0	11	**90**
Enhancing communication	59	2	12	**86**	57	0	11	**90**
Visual supports	54	4	44	52	57	2	26	**72**
Responding to a child's cues	55	0	7	**93**	56	0	4	**96**
Pace of feeding	56	0	11	**89**	56	0	0	**100**
Physical supports	44	5	14	**82**	57	4	16	**81**
Medication	47	4	9	**87**	57	2	7	**91**
Energy supplements	42	2	29	**69**	55	0	27	**73**
Vitamin or nutritional supplements	54	0	15	**85**	55	0	26	**75**
Oral and sensory desensitisation	54	6	13	**82**	57	9	16	**75**
Oral-motor exercises	50	4	26	**70**	57	35	30	35
Graded exposure to new food	60	3	27	**70**	57	4	12	**84**
Graded exposure to new textures	59	2	2	**76**	57	0	19	**81**
Changing behaviour at mealtimes	59	7	36	58	57	2	42	56
Modelling	60	2	22	**77**	57	0	18	**83**
Training to self-feed	56	5	39	55	56	4	50	46
Support for parents	60	2	3	**95**	56	0	4	**96**
Sharing information	60	0	0	**100**	57	0	4	**97**
Psychological support for child	52	4	19	**77**	56	4	38	59

The above figures are for those respondents who were able to score individual interventions (i.e. those who had used them) and therefore do not include those who reported being unable to score or for whom data was missing. Percentages were rounded to the nearest whole number and therefore rounded totals are occasionally different to 100%. Scores above the consensus rating of ≥67% are shown in bold.

Supplementary Table 5. Parents’ and health professionals’ ratings of outcomes on Round 1 of the Delphi Survey

	Parents N=81				Health professionals N=76			
	n	Not Important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %	n	Not important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %
General Health	80	1	10	**89**	76	0	7	**93**
Weight	80	6	41	53	76	4	45	51
Height	78	18	51	31	76	18	50	32
Growth	79	0	25	**75**	76	0	24	**76**
Nutrition	81	0	11	**89**	76	0	3	**97**
Child’s enjoyment of mealtimes	80	1	16	**83**	76	0	9	**91**
Parent’s enjoyment of mealtimes	81	7	51	42	76	0	24	**76**
Quality of life of child	81	1	4	**95**	75	0	8	**92**
Quality of life of family	81	1	21	**78**	75	0	13	**87**
Mental health of parent	81	0	17	**83**	76	0	16	**84**
Safety	78	0	3	**97**	75	0	3	**97**
Oral-motor control	76	0	13	**87**	74	3	23	**74**
Efficiency	80	13	44	44	75	5	35	60
Independence	80	13	28	60	75	3	**67**	31
Variety	81	5	44	51	75	4	**73**	23
Amount	81	4	35	62	75	5	55	40
Appetite	81	3	38	59	75	3	53	44
Mealtime behaviour	80	14	45	41	74	10	61	30
Mealtime Interaction	79	4	35	61	74	1	18	**81**
Social participation	80	4	46	50	74	1	22	**77**
Child’s understanding of mealtimes	80	4	45	51	74	4	45	51
Parent’s understanding of child’s EDSD	80	1	10	**89**	72	1	10	**89**

The above figures are for those respondents who were able to score individual interventions (i.e. those who had used them) and therefore do not include those who reported being unable to score or for whom data was missing. Percentages were rounded to the nearest whole number and therefore rounded totals are occasionally different to 100%. Scores above the consensus rating of ≥67% are shown in bold.

Supplementary Table 6. Parents' and health professionals' ratings of outcomes on Round 2 of the Delphi Survey

	Parents N=61				Health professionals N=61			
Outcome	n	Not Important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %	n	Not important (score of 0-3) %	Important but not essential (score of 4-6) %	Essential (score of 7-9) %
General Health	61	0	3	**97**	61	0	2	**98**
Weight	61	0	66	34	61	0	53	48
Height	61	13	**75**	12	61	13	**75**	12
Growth	61	0	18	**82**	61	0	12	**89**
Nutrition	61	0	5	**95**	60	0	2	**98**
Child's enjoyment of mealtimes	61	0	10	**90**	60	0	2	**98**
Parent's enjoyment of mealtimes	61	8	53	39	59	0	22	**78**
Quality of life of child	61	0	2	**98**	59	0	0	**100**
Quality of life of family	61	0	10	**90**	58	0	3	**97**
Mental health of parent	61	0	7	**93**	58	0	3	**97**
Safety	61	0	0	**100**	58	0	0	**100**
Oral-motor control	56	0	14	**86**	58	0	28	**72**
Efficiency	60	13	**70**	17	57	5	49	46
Independence	61	10	48	43	58	3	**69**	28
Variety	61	3	**71**	26	57	4	**84**	12
Amount	61	0	48	53	56	2	**73**	25
Appetite	61	2	53	46	56	2	61	38
Mealtime behaviour	61	8	57	34	57	5	**68**	26
Mealtime Interaction	60	5	30	65	57	0	21	**79**
Social participation	60	10	37	53	57	2	25	**74**
Child's understanding of mealtimes	60	3	38	58	57	2	58	40
Parent's understanding of child's EDSD	60	0	5	**95**	57	0	7	**93**

The above figures are for those respondents who were able to score individual interventions (i.e. those who had used them) and therefore do not include those who reported being unable to score or for whom data was missing. Percentages were rounded to the nearest whole number and therefore rounded totals are occasionally different to 100%. Scores above the consensus rating of ≥67% are shown in bold.