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Children with neurodisability and feeding difficulties: a UK survey of parent-delivered interventions

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ABSTRACT

Background Eating, drinking and swallowing difficulties (EDSD) are common in children with neurodisability, and have physical and non-physical causes. EDSD have substantial impacts on the child and family. Little is currently documented about what advice is usually given by professionals, including the interventions commonly used, and what informally constitutes 'best clinical practice'. We aimed to identify current UK practice of parent-delivered interventions for EDSD for children with neurodisability, and the outcomes valued by professionals and parents.

Methods Two populations were sampled: health professionals working with children and young people (aged 0–18 years) with neurodisability who experience EDSD (n=421); parents of children with neurodisability aged up to 12 years who experience EDSD (n=359). Questionnaires were developed based on the findings from updates of three systematic reviews, a mapping review of interventions used with this population, and in consultation with health professionals and parents. The questionnaires were distributed through UK health professional and parent networks and mainstream and specialist schools.

Results Diverse professional groups, including speech and language therapists, occupational therapists, paediatricians and dietitians, support children with EDSD and neurodisability. A range of parent-delivered interventions, such as food and drink modification, positioning and modification of mealtime environment, were recommended by health professionals and are used by and acceptable to parents. Health professionals thought the interventions were effective but parents' views were less consistent. Both health professionals and parents rated better general health and improved nutrition as the most important outcomes.

Conclusions These survey findings outline current UK practice of parent-delivered interventions for EDSD in young children with neurodisability. The survey suggests key outcomes to measure in assessing the effectiveness of interventions. Further research is now needed to fully evaluate the effectiveness of interventions and move towards an evidence-based approach to best practice.

What is known about the subject?

- Eating, drinking and swallowing difficulties (EDSD) are common in children with neurodisability and have physical and non-physical causes.
- EDSD have a substantial impact on a child and family.
- Little is documented about the advice usually given by health professionals, the interventions commonly used and what constitutes 'best clinical practice'.

What this study adds?

- A wide range of parent-delivered interventions are recommended by health professionals and used by parents to support young children with neurodisability and EDSD.
- Many interventions are viewed by parents as acceptable to deliver at home although views on their effectiveness are mixed.
- Better general health and improved nutrition are viewed as the most important outcomes for young children with neurodisability and EDSD by health professionals and parents

INTRODUCTION

Long-term conditions affecting the brain, nerves and muscles are often grouped under the term 'neurodisability'.[1] Eating, drinking and swallowing difficulties (EDSD) are common in children with neurodisability, and have physical and non-physical causes. Physical causes relate to reduced muscle control and coordination, impairing the efficiency and safety of sucking, chewing and swallowing. Non-physical causes include sensory sensitivities, such as extreme sensitivity to certain textures or flavours, and rigidity or rituals associated with food or mealtimes. Physical and non-physical EDSD frequently coexist (referred to hereon as mixed EDSD).

EDSD have substantial impacts on children and families. They lead to inadequate calorie intake or a restricted diet, affecting a child's nutrition, growth and general physical health.[2] EDSD make mealtimes stressful for children and their families and impact negatively on quality of life and social participation. For example, a child who requires smooth textured food may be fed separately from family mealtimes, missing social interaction; a child who will eat only a small range of foods or refuses to eat at the table may likewise miss out; both situations cause parental stress. In the UK, parents and carers of children with neurodisability and EDSD are supported by multidisciplinary teams (MDTs) of health professionals.[3] Following assessment, individualised advice is given to parents and carers on how and what to feed their child to improve the safety and efficiency of eating and drinking, the volume of oral solids and liquids if children can eat and drink safely, and how to manage behaviour so mealtimes are a positive experience.[4] Advice often comprises multiple interventions to address a child's EDSD holistically.

The need for robust evidence about the effectiveness of therapy interventions was ranked as the top priority by young people, parents and professionals in the British Academy of Childhood Disability James Lind Alliance Research Priority Setting Partnership.[5] Little is currently documented about how EDSD are managed, which interventions are commonly used, what constitutes 'best clinical practice' and whether there is robust evidence for the effectiveness of practice.[6–9] Guidance to clinicians is limited; NICE guidance on the treatment of both children with cerebral palsy and children with autism spectrum disorder (ASD)[9 10] recommends health professionals consider assessment and intervention in relation to EDSD, but provides no guidance on assessment or which interventions should be provided. As interventions are time-consuming, involve changes to family feeding routines and are sometimes contrary to parents' beliefs about how their child should be fed,[8 11 12] evidence is needed about whether interventions work.

As part of a larger research programme, Focus on Early Eating, Drinking and Swallowing (FEEDS),[13] we aimed to:

1. Identify which MDT health professionals work with children with EDSD and their parents, and which interventions they recommend
2. Determine if the recommended EDSD interventions are acceptable for families to deliver at home
3. Determine if the recommended EDSD interventions are considered effective by parents and health professionals
4. Identify how the outcomes of EDSD interventions are valued by parents and health professionals

METHODS

Participants

Health professionals working with children and young people (aged 0–18 years) with neurodisability who experience EDSD, and parents of children with neurodisability (aged up to 12 years) who experience EDSD, were recruited. Health professionals were recruited through relevant national bodies, such as the Royal College of Speech and Language Therapists, the College of Occupational Therapy and the British Academy of Childhood Disability. Professionals were also recruited through national and regional neurodisability networks, 24 English National Health Service (NHS) Trusts, special interest dietetic groups and local and national nursing networks. Parents were recruited through national and regional parent networks and charities such as the National Network of Parent Carer Forums, the National Autistic Society and Cerebral Palsy UK, 24 English NHS Trusts, and mainstream and specialist schools. Parents of children with ASD were also recruited through two research databases,[14 15] Full recruitment strategies are outlined elsewhere.[13]

Measure

The questionnaire design was informed by updates of three systematic reviews,[7–9] a mapping review[16 17] of interventions used with this population, and in consultation with health professionals and parents. The research team developed the questionnaire drawing on clinical expertise and best practice in survey design.[18] Parallel versions were developed for health professionals and parents, ensuring wording and terminology were appropriate yet comparable (see online supplemental appendices 1 and 2).

The questionnaire comprised three sections: (1) respondent's demographic characteristics; (2) items about interventions, including usage (Do you use it?), effectiveness (In your opinion, is it effective?), acceptability (Was it acceptable to you to deliver at home?), timescales for change (Over what timescale does change usually occur?) and training (Is training given to parents?); (3) important outcomes (What do you think are the potential benefits of interventions for EDSD? From the list of outcomes, which are the most important for the child, parents and family?). Health professionals were also asked how they assessed outcomes.

The questionnaire asked about 25 interventions (see table 1) and 32 outcomes (see table 2), with the option to add other interventions and outcomes. Most questions offered fixed-choice responses; there were opportunities for free-text responses (eg, to provide details of the explanation/diagnosis around the child's EDSD). Questions on respondent demographics and experience of using each intervention were compulsory for completion. Respondents only answered questions regarding further detail about each intervention they used (eg, whether it was acceptable to deliver).

Patient and public involvement

Parent coinvestigators codesigned the research. Parents and health professionals were consulted on the list of interventions and outcomes to be included and supplementary questions, including the acceptability and effectiveness of

Table 1 Interventions presented in the survey

Intervention	Description
Positioning	Ensuring a child has the best posture to eat and drink food safely and efficiently
Manoeuvres	Giving direct physical support to a child when eating or drinking to improve the movements needed to bite, chew and swallow
Oral-motor exercises	Exercises done with a child with the aim of improving their control of their mouth, jaw, tongue or lips
Medication	Any prescribed medicine that could affect eating and drinking
Schedule of meals	Setting the timing of mealtimes to encourage a child's appetite and readiness to eat and drink, and establish a mealtime routine
Food or drink modification	Changing aspects of the child's food or drink, such as the consistency, temperature, taste, amount or presentation
Modification of utensils	Using different spoons, forks, plates, cups or bottles
Modification of the environment	Changing the physical or social setting at mealtimes
Sensory aids	For example, glasses or hearing aids
Energy supplements	Any energy or calorie supplement given orally or via feeding tube
Training to wait for a child's cues for feeding	Helping parents/caregivers to recognise the signs that a child is ready to take another mouthful of food or drink
Pacing of food at mealtimes	Changing the speed at which each mouthful of food or drink is taken by a child
Enhancing child/feeder communication strategies at mealtimes	Improving interaction between a child and the person feeding them during mealtimes
Modifying social eating and drinking opportunities	Any change in the physical environment or behaviour of others when children eat or drink in company
Hand-over-hand prompting	Physically guiding the child's hand to encourage them to grasp or move food/equipment
Counselling	Collaboration between professional and parent to enhance understanding of causes, extent and impacts of eating and drinking difficulties and promote parents' well-being
Desensitisation programme for food avoidance	Activities aimed at gradually introducing a child to new or previously rejected foods and drinks
Desensitisation programme for oral sensations	Activities aimed at reducing a child's adverse reactions to different sensory experiences linked to eating and drinking
Sensory stimulation	Touch-based stimulation on and around the lips and mouth in an attempt to reduce sensory based eating and drinking difficulties
Sensorimotor therapies	Interventions focusing on both sensation (vision, hearing, smell, taste, touch and proprioception) and motor output for learning new skills
Sharing information on the impact of sensory difficulties on eating and drinking	
Sharing information on the impact of movement difficulties on eating and drinking	
Strategies/programmes aimed at changing behaviour at mealtimes	Strategies to encourage a child to behave appropriately at mealtimes
Visual supports	Use of pictures, a 'countdown clock' or social stories to increase a child's understanding of what happens during mealtimes
Modelling	Giving a child the opportunity to learn from others by eating and drinking with them

interventions and time taken to achieve change. Parent coinvestigators contributed to questionnaire design, advising on use of language and clear descriptions of interventions. Online and paper versions of the questionnaire were piloted by parents and health professionals. A Parent Advisory Group (PAG) considered a summary of the survey findings and whether the findings were consistent with their experiences of supporting their child with EDSD,

Table 2 Outcomes presented in the survey

Category	Outcomes
Child physical health	Better general health (eg, less colds or infections) Better sitting Fewer abnormal or unusual movements Fewer/shorter hospital admissions Improved nutrition Increased growth Less pain Weight gain
Eating, drinking and swallowing performance	Better coordination of swallowing and breathing Better oral-motor function (eg, chewing, biting) Fewer breathing changes (any of rate, noise, effort, coughing, antibiotics courses, chest infections) linked to eating, drinking and swallowing Less aversion/avoidance of particular foods Less drooling Less food/drink spilled from lips More food/drink consumed Shorter mealtimes Wider range of foods eaten
Child's quality of life and participation	Better mealtime one to one interaction with child Better quality of life for child Better self-feeding/independence skills Child able to communicate better for example, to express preferences or make choices Child enjoys mealtimes more Child less frustrated or distressed at mealtimes More involvement in family's activities for example, eating with family or outside of the home
Parent/carer/family-related outcomes	Being able to eat a meal somewhere outside the home Better understanding of child's difficulties and strategies to support them Less food waste/reduced cost of food Less parental/carer stress More opportunity to talk to others about feelings about child's eating and drinking difficulties Not having to prepare separate meals for the child Parent/carer enjoys mealtimes more Parent/carer less frustrated or distressed at mealtimes

and service provision. The PAG was recruited through social media and community networks. There was equal representation from parents of children with physical and mixed EDSD and children with non-physical EDSD. Their children's age ranged from 6 to 16 years (for further details see Parr *et al* 2021).[13]

Procedure

Recruitment was from March to September 2018. The questionnaire was distributed by email, and hosted on Qualtrics,[19] with paper versions available. Letters were sent to potential participants with a link to the appropriate version of the questionnaire. Respondents were offered the opportunity to enter a prize draw to win 1 of 10 £100 vouchers. The FEEDS study protocol was followed throughout and there were no deviations (see online supplemental appendix 3).

Analysis

Data were analysed using SPSS V.24.0.[20] Analysis was descriptive, mostly reporting percentages of respondents in each question category. Information on the use of interventions with children with physical EDSD and mixed EDSD was combined as consultation with parents and health professionals found most children with primarily physical EDSD also have nonphysical EDSD.

Table 3 Characteristics of the health professionals and parents who responded

Health professionals	n (%)	Parents	n (%)
Role		**Role**	
Speech and language therapist	131 (31.1)	Mother	332 (92.5)
Occupational therapist	63 (15)	Father	19 (5.3)
Physiotherapist	57 (13.5)	Carer of looked after child	6 (1.7)
Paediatrician	50 (11.9)	Other	2 (0.6)
Dietitian	40 (9.5)		
Nurse	32 (7.6)		
Health visitor	14 (3.3)		
Clinical psychologist	9 (2.1)		
Gastroenterologist	1 (0.2)		
Other	24 (5.7)		
Type of EDSD worked with		**Type of EDSD of their child**	
Physical difficulties	74 (17.6)	Physical difficulties	74 (20.6)
Non-physical difficulties	32 (7.6)	Non-physical difficulties	183 (51.0)
Mixed difficulties	314 (74.6)	Mixed difficulties	91 (25.3)
Missing	1 (0.2)	Missing	11 (3.1)
Employer		**Ethnicity**	
NHS	366 (86.9)	White	318 (88.6)
Education	21 (5.0)	Black/African Caribbean Black British	5 (1.4)
Voluntary sector	13 (3.1)	Asian/Asian British	24 (6.7)
Independent practitioner	15 (3.6)	Mixed/multiple ethnic group	9 (2.5)
Other	5 (1.2)	Other ethnic group	0 (0)
Missing	1 (0.2)	Prefer not to say	3 (0.8)
Settings worked in*		**Primary diagnosis of their child**	
Community services	301 (71.5)	Autism spectrum disorder	183 (51.0)
Hospital (secondary and tertiary services)	151 (36.1)	Down syndrome	69 (19.2)
Education	171 (40.6)	Cerebral palsy	30 (8.4)
Other	13 (3)	Developmental delay	26 (7.2)
		Genetic condition	23 (6.4)
		Learning/intellectual disabilities	4 (1.1)
		Structural brain disorder	4 (1.1)
		Other	19 (5.3)
		Missing	1 (0.2)

*Percentages add up to greater than 100% because respondents could choose more than one option.
EDSD, eating, drinking and swallowing difficulties.

RESULTS

A total of 421 health professionals and 359 parents responded and were included in analysis. Table 3 outlines the respondent characteristics. Online supplemental appendix 4 shows participant study flow.

Characteristics of health professionals

Respondents reported working with infants, toddlers, preschool and school-aged children. Experience of working with children with neurodisability ranged from 0 to 38 years (mean: 12 years 2 months, SD: 8 years 8 months). Most respondents were NHS employed (86.9%) and worked in community services (71.5%) with many working across multiple settings. Most health professionals worked with children with mixed EDSD (74.6%). All respondents worked with all types of EDSD, except clinical psychologists, who reported working only with children with non-physical or mixed EDSD, and dietitians and physiotherapists, who reported only working with children with physical or mixed EDSD (see figure 1). Respondents worked alongside other professional groups including dietitians, speech and language therapists, paediatricians and occupational therapists.

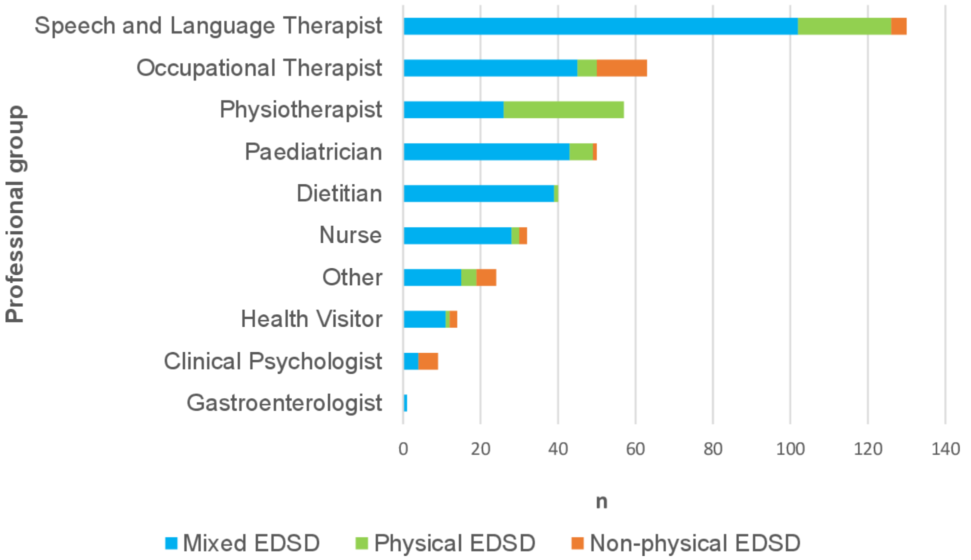

Figure 1 Type of EDSD worked with by professional group. EDSD, Eeating,drinking and swallowing difficulties.

Most health professionals (87.9%) worked with parents to deliver interventions; 68.6% worked with education professionals.

Characteristics of parents

Most parent respondents were aged 31–50 years (85.0%), and 92.5% were mothers. Half of respondents were parents of children with non-physical difficulties (51.0%), who reported their child's main diagnosis as ASD. Respondents' children's ages ranged from 2 months to 12 years 11 months (mean: 7 years 5 months, SD 3 years 3 months); most had ongoing EDSD difficulties (88.0%).

Health professionals' recommendation and delivery of EDSD interventions

Health professionals reported using a wide range of interventions (most used multiple interventions, median: 11, range: 0–25) (table 4) across a range of settings, including family homes, education and NHS settings. They trained parents to deliver interventions (mean across interventions: 91.1%, range: 73.7%–97.0%) and provided ongoing family support (mean 57.9%, range: 41.7%–85.5%).

Parents' use of and views on acceptability of EDSD interventions

Table 5 shows the frequency of parent use of each intervention. Parents thought that all interventions recommended by health professionals were acceptable to deliver at home (mean: 94.0%, range: 80.0%–100%).

Effectiveness of EDSD interventions

Most health professionals reported that the interventions used were effective (mean: 98.5%, range: 90.9%–100%). Parents' views were less consistent (mean: 48.8%, median: 51.4%, range: 29.6%–64.7%). For parents of children with physical and mixed EDSD, the interventions most frequently rated as effective were energy supplements (67.5%), hand-over-hand prompting (64.2%), modification of utensils (63.3%), modification of environment (63.0%) and food or drink modification (62.8%). For parents of children with non-physical EDSD, the interventions most frequently rated as effective were sensorimotor therapies (100%), sensory aids, (64.3%), energy supplements (60.7%) and hand-over-hand prompting (58.5%).

Evaluation of outcomes

Health professionals and parents agreed the two most important outcomes to measure in assessing the success of interventions were improved nutrition (parents 39.8%; health professionals 30.9%) and better general health (parents 30.9%; health professionals 31.6%) (table 6). All other outcomes important to parents related to children's physical health; by contrast, health professionals prioritised outcomes related to child and family well-being, including better child quality of life and less parent/caregiver stress.

DISCUSSION

This large UK survey found a wide range of interventions were used for children with EDSD and most children received multiple interventions. Parents found EDSD interventions acceptable to use at home. Health professionals perceived EDSD interventions used as effective, while parents' views were less consistent. Both parents and professionals said the most important outcomes to measure were nutrition and general health. The findings are an important step in developing an evidence base about the effectiveness of EDSD interventions.

This survey identified the range of health professionals working with children who have EDSD, highlighting the diversity of needs. Most professionals reported working with children with mixed EDSD. A wide range of interventions addressed physiological and behavioural needs. Most interventions were used with all types of EDSD, indicating

Table 4 Use of interventions by health professionals overall and split by causes of EDSD

Intervention	All N=421, n (%)	Physical and mixed EDSD n=388, n (%)	Non-physical EDSD n=32, n (%)
Positioning	325 (77.2)	307 (79.3)	17 (53.1)
Food or drink modification	237 (56.3)	221 (57.0)	15 (46.9)
Modification of environment	218 (51.8)	195 (50.3)	22 (68.8)
Information on impact of sensory difficulties on eating and drinking	213 (50.6)	195 (50.3)	17 (53.1)
Information on impact of movement difficulties on eating and drinking	207 (49.2)	198 (51.0)	8 (25.0)
Desensitisation programme for food avoidance	204 (48.5)	185 (47.7)	18 (56.3)
Modification of utensils	193 (45.8)	178 (45.9)	15 (46.9)
Pacing of food at mealtimes	179 (42.5)	168 (43.3)	10 (31.3)
Medication	167 (39.7)	162 (41.8)	5 (15.6)
Enhancing child/feeder communication strategies at mealtimes	161 (38.2)	143 (36.9)	17 (53.1)
Schedule of meals	157 (37.3)	143 (36.9)	14 (43.8)
Manoeuvres	152 (36.1)	149 (38.4)	2 (6.3)
Strategies/programme aimed at changing behaviour at mealtimes	146 (34.7)	129 (33.3)	17 (53.1)
Training to wait for child's cues for feeding	136 (32.3)	130 (33.6)	6 (18.8)
Visual supports	133 (31.6)	115 (29.7)	18 (56.3)
Hand-over-hand prompting	129 (30.6)	118 (30.4)	11 (34.4)
Counselling	120 (28.5)	109 (28.1)	11 (34.4)
Desensitisation programme for oral sensations	109 (25.9)	100 (25.8)	9 (28.1)
Modifying social eating and drinking opportunities	103 (24.5)	89 (23.0)	14 (43.8)
Oral-motor exercises	102 (24.2)	93 (24.0)	9 (28.1)
Energy supplements	88 (20.9)	87 (22.4)	1 (3.1)
Sensory stimulation	60 (14.3)	56 (14.5)	4 (12.5)
Sensory aids	58 (13.8)	55 (14.2)	3 (9.4)
Modelling	52 (12.4)	43 (11.1)	9 (28.1)
Sensorimotor therapies	12 (2.9)	10 (2.6)	2 (6.3)

The numbers within each subgroup (physical and mixed EDSD and non-physical EDSD) do not add up to the total number of respondents due to one health professional not providing information on type of EDSD worked with. These percentages add up to greater than 100% because participants could choose more than one option. The percentage of missing data varied for each of the interventions (mean=23%, SD=5%) for each of the groups.

overlap in approach, regardless of the cause of the child's difficulties. This highlights the importance of MDTs and is inline with the concept that an individual's functional characteristics should form the basis for planning interventions rather than their neurodevelopmental diagnosis.[21]

Parents thought all interventions recommended by health professionals were acceptable to deliver at home, despite some being time-consuming and involving considerable changes to usual family feeding routines. Parents were less consistent about whether specific interventions were effective. One reason for this discrepancy might be that the training parents received was not sufficient to enable them to optimally deliver the intervention. Other reasons may be that competing demands on parents' time resulted in the intervention being implemented inconsistently or that interventions are only effective for some children. These explanations are inline with the views of health professionals gathered within a recent qualitative study by Beresford *et al.*[22] Our findings therefore emphasise the importance of person-centred practice and support the assessment of families' readiness and willingness to use different interventions when deciding how best to support children with EDSD and neurodisability, and directly monitoring intervention effects.

Key outcomes for intervention were general health and nutrition, demonstrating parents and professionals prioritised child physical health over other outcomes. Clarity on the key outcomes is an important step towards understanding how to evaluate healthcare interventions and in future effectiveness studies. Our wider programme included a measurement properties review of tools to

Table 5 Use of interventions by parents overall and split by causes of EDSD

Intervention	All N=359*, n (%)	Physical and mixed EDSD n=165†,n(%)	Non-physical EDSD n=183‡, n (%)
Food or drink modification	203 (56.5)	113 (68.5)	88 (48.1)
Desensitisation programme for food avoidance	167 (46.5)	83 (50.3)	83 (45.4)
Modification of utensils	146 (40.7)	79 (47.9)	65 (35.5)
Enhancing child/feeder communication strategies at mealtimes	146 (40.7)	61 (37.0)	85 (46.4)
Positioning	145 (40.4)	102 (61.8)	41 (22.4)
Information on impact of sensory difficulties on eating and drinking	140 (39.0)	56 (33.9)	83 (45.4)
Modification of environment	130 (36.2)	46 (27.9)	84 (45.9)
Hand-over-hand prompting	123 (34.3)	81 (49.1)	41 (22.4)
Visual supports	122 (34.0)	41 (24.8)	81 (44.3)
Medication	121 (33.7)	89 (53.9)	30 (16.4)
Schedule of meals	121 (33.7)	48 (29.1)	71 (38.8)
Strategies/programme aimed at changing behaviour at mealtimes	109 (30.4)	29 (17.6)	80 (43.7)
Modifying social eating and drinking opportunities	83 (23.1)	37 (22.4)	45 (24.6)
Pacing of food at mealtimes	78 (21.7)	45 (27.3)	31 (16.9)
Oral-motor exercises	74 (20.6)	54 (32.7)	19 (10.4)
Energy supplements	68 (18.9)	40 (24.2)	28 (15.3)
Sensory aids	62 (17.2)	34 (20.6)	28 (15.3)
Sensory stimulation	60 (16.7)	37 (22.4)	21 (11.5)
Desensitisation programme for oral sensations	59 (16.4)	38 (23.0)	20 (10.9)
Training to wait for child's cues for feeding	53 (14.8)	34 (20.6)	18 (9.8)
Information on impact of movement difficulties on eating and drinking	50 (13.9)	37 (22.4)	12 (6.6)
Manoeuvres	38 (10.6)	35 (21.2)	3 (1.6)
Modelling	37 (10.3)	22 (13.3)	15 (8.2)
Counselling	17 (4.7)	4 (2.4)	12 (6.6)
Sensorimotor therapies	11 (3.1)	9 (5.5)	2 (1.1)

The numbers within each subgroup (physical and mixed EDSD and non-physical EDSD) do not add up to the total number of respondents due to 11 parents not providing information on the nature of their child's difficulties. These percentages add up to greater than 100% because participants could choose more than one option. The percentage of missing data varied for each of the interventions and for each of the groups. The following show the mean per cent of missing data for each group and SD in brackets):
*11% (3%),
†8% (1%).
‡10% (4%).
EDSD, eating, drinking and swallowing difficulties.

Table 6 Top five most important outcomes identified by parents and healthcare professionals

Health professionals, N=421		Parents, N=359	
Outcome	n (%)	Outcome	n (%)
Better general health	133 (31.6)	Improved nutrition	143 (39.8)
Improved nutrition	130 (30.9)	Better general health	111 (30.9)
Better quality of life for child	110 (26.1)	Weight gain	76 (21.2)
Fewer or shorter hospital admissions	73 (17.3)	Increased growth	65 (18.1)
Less parental or carer stress	73 (17.3)	Wider range of foods eaten	65 (18.1)

measure change in EDSD, to inform the selection of outcome measures in future effectiveness studies.[13]

Limitations

This survey was completed by a large number of parents and health professionals; however, dissemination methods did not allow response rate calculation from participant groups or appraisal of the extent and nature of potential response bias. High numbers of responses were received from speech and language therapists but fewer responses from other professional groups (eg, health visitors and clinical psychologists). Respondents may have had stronger views or more experience of using interventions than non-responders, introducing bias. Although the number of respondents was sufficiently large to address the aims of this study, the survey was not sufficiently powered for subgroup analysis, such as how different types of professionals deliver interventions.

Limited information was available about the frame of reference used by health professionals responding (eg, child age), with most respondents reporting that they worked across the age range 0–18 years. Health professionals were only asked to report the EDSD type of the children with whom they worked (physical, non-physical or mixed EDSD); this limited opportunities for exploration of differences between how professionals work with children from different EDSD types.

Finally, parents and professionals may have found it difficult to rank outcomes due to the choices offered for example, choosing between a child health-related outcome and a parent quality of life outcome.

CONCLUSIONS

This is a large-scale survey of current UK practice of parent-delivered interventions for EDSD in young children with neurodisability. It demonstrates the diversity of interventions used with and needed by this group of children and the overlap in approaches across the different EDSD types. It also identifies the key outcomes important to both parents and health professionals. These findings provide a synthesis of the evidence on interventions and are an important first step in developing a toolkit of interventions (see Parr *et al* 2021 for further details).[13]

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Contributors JP was chief investigator, co-led the design and delivery of the study and supervised data analysis. LP co-led the design and delivery of the project. HT undertook data collection and analysis. CB, CM, JC, DS, JS, DG, JT and EM contributed to the design of the survey. 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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