

"This is the peer reviewed version of the following article: Sellers, D, Pennington, L, Bryant, E, Benfer, K, Weir, K, Aboagye, S, et al. Mini-EDACS: development of the Eating and Drinking Ability Classification System for young children with cerebral palsy. *Dev Med Child Neurol*. 2022; 64: 897–906., which has been published in final form at <https://doi.org/10.1111/dmcn.15172>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions. This article may not be enhanced, enriched or otherwise transformed into a derivative work, without express permission from Wiley or by statutory rights under applicable legislation. Copyright notices must not be removed, obscured or modified. The article must be linked to Wiley's version of record on Wiley Online Library and any embedding, framing or otherwise making available the article or pages thereof by third parties from platforms, services and websites other than Wiley Online Library must be prohibited."

1 Mini-EDACS: development of the Eating and Drinking Ability Classification System for young
2 children with cerebral palsy

3 **D Sellers¹, L Pennington², E Bryant³, K Benfer⁴, K Weir⁵, S Aboagye⁶, C Morris⁷**

4 ¹Chailey Clinical Services, Sussex Community NHS Foundation Trust, Lewes, UK; ²Institute of
5 Health and Society, Newcastle University, Newcastle, UK; ³School of Health Sciences,
6 University of Brighton, Brighton, UK; ⁴Queensland Cerebral Palsy and Rehabilitation
7 Research Centre, Child Health Research Centre, Faculty of Medicine, University of
8 Queensland, Brisbane, Australia; ⁵Gold Coast Campus, Griffith University, Southport,
9 Australia; ⁶Department of Speech, Language and Hearing Sciences, University of Health and
10 Allied Health Sciences, Ghana; ⁷University of Exeter, Exeter, UK

11 **Aim:** This study aimed to develop and test Mini-EDACS to describe developing eating and
12 drinking abilities of children with CP aged between 18 and 36 months. The existing Eating
13 and Drinking Ability Classification System (EDACS) was modified to define Mini-EDACS
14 content.

15 **Methods:** Mini-EDACS was developed in 3 stages: i) EDACS was modified after application to
16 videos of standardised feeding evaluations of children with CP aged 18-36 months ($n=130$);
17 ii) refined content and validity of Mini-EDACS was established through an international
18 Delphi survey; iii) inter-observer reliability was assessed by comparing Mini-EDACS levels
19 assigned by speech and language therapists (SaLTs) from video data and parent report.

20 **Results:** Mini-EDACS provides age-appropriate descriptions for children 18-36 months with
21 CP. 89 stakeholders participated in the Delphi survey; required levels of agreement were
22 met after one round (i.e. >80% agreement). 13 SaLTs completed paired ratings from 43
23 video recordings: absolute agreement: 58%; kappa: 0.43; ICC: 0.78 (95% CI 0.63-0.87).

24 **Interpretation:** Mini-EDACS provides a valid system for classifying eating and drinking
25 performance of children with CP under three years old. Results suggests moderate
26 agreement and good reliability when rating Mini-EDACS level from video recordings of
27 young children with CP.

28

29

30

31

32

1 WHAT THIS PAPER ADDS:

- 2 • The Mini-EDACS expands the scope of the Eating and Drinking Ability Classification
3 System (EDACS) to provide a new valid and reliable system for classifying eating and
4 drinking performance of infants with CP under three years of age.
- 5 • Mini-EDACS describes the spectrum of eating and drinking ability from age 18 – 36
6 months, providing a context for parents and therapists to evaluate and reflect on
7 development and management of eating and drinking in the early years.

8

1 INTRODUCTION

2 People with cerebral palsy (CP) are affected by a range of activity limitations, attributed to
3 non-progressive disturbances occurring in the developing fetal or infant brain [1]. The motor
4 disorders of CP are often accompanied by disturbances of sensation, perception, cognition,
5 communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems [1,
6 p. 9]. Impairments can limit the oral skills required for eating, drinking and swallowing, with
7 consequent risks for respiratory problems linked to direct aspiration of food and fluid into
8 the lungs [2] [3], and inadequate nutrition and hydration [4] [5]. Limitations to movement
9 may affect how someone brings food and drink to the mouth. The degree to which a person
10 with CP can control the posture and movement of the trunk and head has a direct impact on
11 the efficient use of the muscle systems which support feeding and breathing [6] [7].

12

13 Whilst the brain lesion causing CP may be detected in early brain imaging and neurological
14 signs may be detected in clinical tests, the severity and type of CP is more challenging to
15 determine in the first years of life [8]; early development and functional ability are
16 influenced by numerous factors including age, circumstances and opportunity, general
17 health, and concomitant medical conditions. The development of functional classification
18 systems to describe the impact of CP on an individual's daily function represent an
19 important paradigm shift [9]. The impetus to develop classifications of functional ability to
20 accurately reflect age related differences in individuals with CP has been spearheaded by
21 the developers of the Gross Motor Function Classification System Expanded and Revised
22 (GMFCS E&R) [10] and Manual Ability Classification System (MACS) and Mini-MACS [8].

23

24 The Eating and Drinking Ability Classification System (EDACS) [11] describes the spectrum of
25 eating and drinking ability of individuals with CP from 3 years of age; measures of reliability
26 for 100 children with CP include kappa 0.72 and ICC 0.93 (95% CI 0.90-0.95). Content,
27 construct and concurrent validity of the EDACS have been demonstrated, alongside
28 evidence that EDACS is broadly reliable in clinical and research contexts when used by
29 experienced clinicians and parents for individuals aged 3-22yrs [11] [12] [13] [14]. EDACS has
30 been translated into more than twenty-two languages and validated in Chinese [15],
31 German [13] and Dutch [12]. EDACS describes functional eating and drinking ability for
32 people with CP from three years in two distinct ordinal scales. EDACS identifies the key

1 features of **safety** (choking and aspiration risk) and **efficiency** (time taken in relation to
2 peers and loss of food and fluid from the mouth) linked with limitations to oral skills
3 required for biting, chewing and swallowing in a 5-level ordinal scale. Descriptions of five
4 distinct levels of ability include information about biting, chewing and swallowing ability,
5 food and fluid textures that are managed, breath changes associated with eating and/or
6 drinking, and risks to health linked to aspiration or choking. The Levels of assistance
7 required at mealtimes are described in a separate three level ordinal scale: Independent,
8 Requires Assistance and Totally Dependent. EDACS is analogous and complementary to
9 Gross Motor Function Classification System (GMFCS) [10], Manual Ability Classification
10 System (MACS) [16] or Communication Function Classification System (CFCs) [17].

11

12 Benfer et al. examined the eating, drinking and swallowing skills of a group children with CP,
13 aged 18 to 36 months. Using standardised measures of paediatric oro-pharyngeal
14 dysphagia, they found 65% of children with CP experienced eating, drinking and swallowing
15 difficulties, and a stepwise relationship between oro-pharyngeal dysphagia and GMFCS level
16 [18]. Oro-pharyngeal dysphagia was present across all levels of gross motor severity;
17 therefore they recommended proactive screening of all young children with CP, to improve
18 growth and nutritional outcomes and respiratory health [18]. Hence there is value in
19 extending the scope of EDACS to capture early eating and drinking abilities of children with
20 CP under 3 years.

21

22 **METHOD**

23 Mini-EDACS development involved three distinct stages, derived from processes set out by
24 developers of GMFCS [10], MACS [16] [8], CFCs [17] and EDACS [11]. Mini-EDACS draft was
25 constructed by applying EDACS to existing longitudinal video recordings of standardised
26 feeding evaluations of children with CP, aged 18 to 36 months ($n=130$) [19]. The content of
27 EDACS was modified to describe distinct levels of ability and mealtime performance for
28 younger children with CP. The content validity of Mini-EDACS was examined and revised
29 within two rounds of an online Delphi Survey [20] [21] until agreement about content was
30 reached. The final stage assessed inter-observer reliability among speech and language
31 therapists (SaLTs). Research Ethics approval was granted by NHS Health Research Authority,
32 London–South East Research Ethics Committee, REC reference 17/LO/1557; Research

1 Governance was provided by Research & Innovation Department, Sussex Community NHS
2 Foundation Trust.

3

4 **Stage 1: Drafting revised content of Mini-EDACS**

5 ***Procedures:***

6 Modifications to original EDACS descriptions of eating and drinking ability were made with
7 reference to video data collected as part of a longitudinal study of children with CP (n=130)
8 aged 18 to 36 months [19]. The age range of children observed in this study established ~~the~~
9 upper and lower age limits for Mini-EDACS. Eating and drinking abilities of this cohort were
10 studied as part of a project led by researchers within Queensland Cerebral Palsy and
11 Rehabilitation Research Centre, Child Health Research Centre, The University of
12 Queensland, Australia. The Research Centre (KB and KW) hold data collected as part of the
13 study, including video recordings of standardised assessments using Schedule of Oral Motor
14 Assessment and Dysphagia Disorders Survey. KB and KW applied descriptors from EDACS
15 levels to the recorded eating, drinking and swallowing abilities of each child aged 18 to 36
16 months. Headings derived from EDACS algorithm (**Figure 1**) were used to classify the young
17 children. Detailed descriptions under each of these headings were then scrutinised by KB
18 and KW to identify where modifications were needed, reflecting the developing eating and
19 drinking skills of younger children. Changes to original EDACS wording were proposed and
20 agreed with the Project Team, which included three developers of EDACS (DS, LP and CM)
21 and four experienced speech and language therapists (KB, KW, DS and LP).

22

23 ***Results:***

24 Headings of the existing 5 level ordinal scale, used to define eating, drinking and swallowing
25 ability using key features of **safety** and **efficiency**, appeared to be suitable for the younger
26 age range (**Figure 1**).

27

28 The separate 3 level ordinal scale describing *Level of Assistance* required to bring food and
29 drink to the mouth was also unchanged: *Independent* – individuals are able to bring food
30 and drink to their own mouth without any assistance; *Requires assistance* – an individual
31 needs help to bring food or drink to the mouth, either from another person or through the
32 use of adapted equipment; *Totally dependent* – an individual is totally dependent upon

1 another to bring food or drink to the mouth. Whilst the descriptions remained the same, it
2 was recognised that younger children will require more assistance at mealtimes because of
3 their developing skills.

4

5 Adjustments were made to **Descriptions** of different levels to reflect observed differences in
6 eating and drinking abilities of younger children with CP, including: i) more food and fluid
7 loss is expected; ii) more limited selective oral movement is likely; iii) different drinking
8 receptacles are used including bottles, breast, spouted cups; iv) hands are used to
9 manipulate food more often than cutlery; v) higher levels of mealtime assistance are
10 needed; vi) spitting out non-preferred or unfamiliar food and exploring food with hands is
11 common; vii) mealtimes are likely to be messier; viii) protective reflexes such as gagging and
12 coughing are more likely to occur for new and challenging textures, including thin fluid from
13 a cup. Wording in the section describing the *Purpose* of EDACS was slightly modified to refer
14 to the new age levels from 18 to 36 months, and from 3 years to adulthood.

15

16 The remaining EDACS content describing the *Purpose, Background, Key Features of Eating*
17 *and Drinking, User Instructions, Definitions, and General Headings* was unchanged. *User*
18 *Instructions* include an acknowledgement that some aspects of eating and drinking are not
19 possible to see and that it may be helpful to assign a level with a professional who has knowledge
20 about the necessary skills for safe and efficient eating and drinking. *Definitions* includes plain English
21 descriptions of “aspiration”, “signs of aspiration”, and “silent aspiration”. New **Descriptions** were
22 drafted for children with CP aged 18 to 36 months, under each of the original headings.

23 **Table 1** shows the new content of Mini-EDACS including highlighted changes to the original
24 EDACS wording.

25

26 **Stage 2: Delphi Survey to examine content validity of Mini EDACS**

27 ***Participants***

28 265 invitations to participate in the Delphi Survey were sent to clinical and research experts,
29 parent groups, charitable organisations, and individuals who had expressed interest in
30 EDACS through the form required to download EDACS from www.edacs.org. Eight people
31 declined to participate; 32 email invites were undeliverable; 107 invitations received no
32 response. 118 participants agreed to take part in the Delphi Survey and confirmed their

1 availability to participate over a designated 6 months' time period (**Figure S1**). There is no
2 recommended sample size for Delphi Surveys; we aimed to recruit approximately 70
3 experienced stakeholders with knowledge of the eating and drinking abilities of young
4 children with CP [22].

5

6 ***Procedures***

7 Delphi surveys provide a means of structuring group interaction, facilitating equal
8 participation, with the potential to preserve anonymity of participants who contribute their
9 opinions [20] [21]. Feedback from each round is given to participants until stability of group
10 opinion or consensus emerges. Participants were asked to examine the content of the Mini-
11 EDACS represented in a series of 22 statements, using both open ended questions and 7-
12 point Likert scales (where 1=strong disagreement, 4=neither agree or disagree, 7=strong
13 agreement). Participants were asked four questions about their background, years of
14 experience with CP, geographical location of experience with CP and what they considered
15 to be important features of eating and drinking for young children with CP. The final
16 question invited further comment in free text. Questions are listed in **Appendix II**. Surveys
17 were completed by participants either online or through hard copies returned to Research
18 Team. Consensus was defined as more than 80% agreement from participants for all
19 statements representing the Mini-EDACS content [22] [11]. Following Delphi Survey 1, Mini-
20 EDACS content was modified using text-based feedback given by participants. Feedback
21 from Round 1 was summarised and presented to all participants of Delphi Round 1,
22 including the revised content of Mini-EDACS. A second round of Delphi Survey asked for
23 levels of agreement about slight changes made to Mini-EDACS from participants' feedback
24 in two questions using 7-point Likert scale as in Round 1. The procedure of the Delphi
25 Survey followed recommended good practice [23].

26

27 ***Results***

28 Eighty-nine stakeholders participated in Delphi Survey Round 1 to examine Mini-EDACS
29 content. **Table S1** shows demographics of participants. Agreement with EDACS content was
30 defined as participants selecting "slightly agree", "agree" or "strongly agree" from 7-point
31 Likert Scale. In Delphi Round 1, there was 95% to 100% stakeholder agreement for 21 out of
32 22 statements. The lowest level of agreement (92%) concerned the appropriateness of the

1 description of Level V for young children with CP. There were no observable patterns of
2 disagreement across stakeholder groups. Comments received in Round 1 led to a
3 simplification of the wording of two bullet points under Descriptions of Level III. These were
4 accepted by all participants in Round 2. Only 25 out of 89 participants responded to Delphi
5 Survey 2; two email reminders were sent to prompt participation. No new participants were
6 recruited to Round 2.

7

8 **Stage 3: Inter-observer Reliability**

9 ***Participants***

10 Participants in the reliability study comprised 13 speech and language therapists (SaLTs)
11 with specialist knowledge about eating and drinking and CP and more than 2 years'
12 experience, from UK. A convenience sample of forty-three children with CP and their
13 parents and/or carers participated in the study; participants were recruited from specialist
14 settings in the UK, Ghana, Mexico and Italy. Mini-EDACS was used by SaLTs to classify
15 children's eating and drinking ability (30/43 male; age range 18–36 months; mean age 28
16 months, SD 6.7). Other demographic information collected for young children included
17 gender, GMFCS level, presence of feeding tube, and country of residence (see **Table 2**).

18

19 ***Procedures***

20 Video recordings of each child's usual mealtime were made by members of the research
21 team or healthcare professionals, for the purposes of assessing the reliability of Mini-EDACS.
22 The setting was as naturalistic as possible and mealtime duration was variable, reflecting
23 usual routines and abilities of each child. Parents were asked nine questions, either in a
24 written questionnaire or verbally, to provide supplementary information to accompany the
25 video recording to aid classification (**Table S2**). Parent and/or carer responses were
26 recorded verbatim by researcher or healthcare professional and checked for accuracy with
27 parents. Parents and/or carers were invited to use Mini-EDACS to classify their child's eating
28 and drinking ability, using User Instructions and Mini-EDACS descriptions.

29

30 Information for each child comprised the video recording of a typical mealtime and the
31 answers given to nine questions (**Table S2**); each child was randomly assigned to one of 8
32 groups. A pair of independent ratings was obtained for each child. Pairs of SaLTs were

1 assigned to one of these eight groups and directed to use Mini-EDACS to classify each child.
2 Ten SaLTs provided ratings for children in one group only; three SaLTs rated children in two
3 groups. None of the SaLTs were familiar with any of the children in the videos.

4

5 SaLTs and parents and/or carers were asked questions about how easy it was to use Mini-
6 EDACS in a brief paper-based survey, which was returned anonymously to the project team:
7 1) How clear were the directions given; 2) How easy was it to use Mini-EDACS; 3) How clear
8 is the description for each level; 4) Are the distinctions between the levels clear; 5) Any
9 other comments about your experience using Mini-EDACS? No parents, carers or SaLTs
10 received any training in using EDACS; classification was based on instructions provided in
11 Mini-EDACS document (see Appendix III).

12

13 Absolute and chance-corrected agreement (kappa) [24] were calculated between pairs of
14 raters using SPSS software. Kappa was selected as a measure of agreement between raters
15 because it gives equal weight to all disagreements between raters, suitable for both nominal
16 and ordinal data. It allows direct comparison with kappa values in reliability studies
17 conducted for EDACS [11]. Kappa values of 0.41-0.6 indicate moderate agreement, 0.61-
18 0.80 substantial agreement and values between 0.81 and 1.00 almost perfect agreement
19 [25]. Intraclass Correlation Coefficients (ICC, two way random effects single measures
20 consistency) were calculated to assess reliability, that is consistency between raters in
21 assigning EDACS levels to continuous data [26]; ICCs of 0.7 or higher are considered
22 acceptable for measures in groups, and ICCs exceeding 0.9 are regarded as reliable for use
23 clinically with individuals [27].

24

25 **Results**

26 **Table 3** shows results of inter-observer reliability studies. When pairs of SaLTs used Mini-
27 EDACS to rate video recordings of 43 children with CP absolute agreement was 58%,
28 kappa=0.43, indicating moderate agreement [25]. Levels of consistency in use of Mini-
29 EDACS by SaLTs were acceptable: ICC: 0.78 (95% CI 0.63-0.87). SaLTs assigned same level or
30 disagreed by one level only, for all but four children, where disagreement was by 2 levels.
31 Levels of agreement and consistency in use of 3 level ordinal scale indicating Levels of

1 Assistance required were higher: absolute agreement 86%; kappa=0.62; ICC: 0.87 (95% CI
2 0.77-0.93).

3

4 Ease of use questions were answered by 7 professionals and 15 parents who wrote brief
5 free text responses to written questions on paper. All professionals agreed that user
6 directions were clear and that Mini-EDACS was quick and easy to use: technical terms were
7 clearly explained and “jargon busted”. Professionals found the descriptions clear; comments
8 received included it “covers safety aspects well”, that “ratings and descriptions were clear”
9 and that it was “reasonably clear [levels] III vs IV [and level] IV vs V needed discussions”.
10 Professionals found distinctions between levels clear and “particularly helpful”.

11

12 Professionals found the task of completing ratings from videos and parent report to be
13 challenging as they were unable to obtain additional information they considered to be
14 necessary to classify some children. These issues were specific to the research protocol.

15

16 Fifteen parents gave feedback after using Mini-EDACS. All thought instructions were clear.
17 Most parents found Mini-EDACS easy to use; two parents found it challenging because they
18 were unable to read, requiring someone else to read the information to them. All parents
19 found descriptions for each level to be clear: one parent commented that the “tube aspect
20 made me fear a little bit”; another commented “it’s clear because each level spells out the
21 requirements so it was easy to identify the right level for her”. Parents found the
22 distinctions between the levels to be clear and easy to understand: “I thought the
23 distinctions were particularly helpful”. General comments received included: “I was very
24 impressed with EDACS”; “What I learned is that Mini-EDACS will enable every parent to
25 know where their child’s level is”; “No-one had ever discussed a rating score even existed
26 for children with cerebral palsy and I found it overall a positive experience”.

27

28 **DISCUSSION**

29 Development of Mini-EDACS followed an iterative three-staged approach including use of
30 existing video data of young children with CP (18-36 months) to examine and modify the
31 existing content of EDACS, a Delphi Survey to engage the collective expert knowledge and
32 opinions of a wide range of participants and reliability testing. We have demonstrated

1 evidence of the content validity of Mini-EDACS, and that classification is broadly reliable
2 [22]. Mini-EDACS describes functional eating and drinking abilities of young children with CP
3 aged 18 -36 months in one of five distinct levels, thereby extending the lower age limit
4 linked to use of EDACS.

5
6 We have demonstrated the applicability of the EDACS logic model to a younger age group.
7 Mini-EDACS identifies the key features of safety (choking and aspiration risk) and efficiency
8 (time taken in relation to peers and loss of food and fluid from the mouth) linked with
9 limitations to oral skills required for biting, chewing and swallowing. Five distinct levels of
10 ability include information about biting, chewing and swallowing ability, food and fluid
11 textures that are managed, breath changes associated with eating and/or drinking, and risks
12 to health due to aspiration or choking. Breath changes may include changes to respiratory
13 sounds, rate or effort. Modifications made to descriptions under each level I to V reflected the
14 reduced skill level of young children learning to bite, chew and swallow food and drink.
15 Levels of assistance required at mealtimes are described in a separate scale, identical to the
16 original. Because young children are still developing skills, it is likely that EDACS levels will
17 change as children learn to make optimal use of the movement skills they have. Predictive
18 validity of EDACS, and by extension Mini-EDACS, is yet to be examined [28]; there is a lack of
19 evidence to support discussions with families about likely outcomes for their children's
20 eating and drinking abilities overtime.

21
22 When SaLTs used Mini-EDACS to classify levels of assistance required and the eating and
23 drinking ability of young children with CP, from naturalistic video recordings, measures of
24 agreement were moderate [25] with acceptable levels of reliability for groups [27].
25 Reliability data for Mini-EDACS indicates less agreement between raters than values from
26 the original study when pairs of speech and language therapists used EDACS to rate eating
27 and drinking abilities of children with CP that they knew well [11]. Feedback from raters
28 suggested that variability in levels assigned may be linked to lack of information available to
29 them in the video recordings. In the absence of information, SaLTs have to make
30 'assumptions' based on what they are seeing to fill in the gaps and assign a level; clinical
31 experience and other factors could influence agreement more when classifications are
32 made from naturalistic feeding videos [29].

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31

Although information from parents was provided to supplement the video recordings, parental report of their children's general performance was sometimes different from what was observed. Additionally, video recordings were made in different cultural settings which added further levels of unfamiliarity for raters, including new food and fluid types, utensils, and novel postural management solutions. There was also variability in whether mealtime assistance was provided by familiar or unfamiliar carers.

Some therapists were concerned that some young children were continuing to eat and drink although signs of aspiration were observed; enteral feeding to supplement or replace oral nutrition for children with CP is not widespread or affordable in Ghana and Mexico. In addition, complex decision making to place a gastrostomy tube may be postponed until it is evident that children's growth is compromised by restricted nutritional intake. It is likely that these are contributory factors to the low number of very young children receiving enteral nutrition in this study (i.e. 7% n=3/43): all 3 children receiving enteral nutrition were classified as GMFCS V; two of these children were classified as EDACS V and one child was classified as EDACS level IV by both SaLT1 and SaLT2. Two children classified as EDACS Level V were reliant on oral nutrition/hydration. In the original EDACS study [11] 34% of children were tube fed across EDACS levels I to V, with 84% (37/44) classified as EDACS IV or V.

EDACS, including Mini-EDACS, offers a system for classifying eating and drinking ability that is distinct from detailed clinical assessments and/or guidelines for mealtime management. It provides a means to distinguish different levels of functional performance to aid communication between people with CP, their parents and different healthcare professionals working in different settings. It provides a context, describing the whole range of ability, for parents to consider and understand their own child's eating and drinking ability. Uptake of EDACS has demonstrated its potential for use in population studies to explore the stability, progression or regression of eating and drinking ability for individuals with CP [28], as well as associations with compromised hydration and nutrition [30], respiratory illness and other health concerns [31].

1 There are a number of limitations to the study. Participants with diverse backgrounds
2 initially accepted the invitation to take part in the Delphi Survey, although 25% did not
3 respond to the survey. Delphi Survey participants indicated high levels of agreement with
4 contents of Mini-EDACS in Round 1, reaching the required level of consensus; however, less
5 than a third of participants responded to questions in Round 2. Only three parents were
6 able to take part in the Delphi Survey. The reliability data sample was less than the
7 recommended number of 50 participants [22]. Raters completed Mini-EDACS classifications
8 using video data of young children who were not known to them. Additionally, UK based
9 therapists were invited to view young children eating and drinking in unfamiliar cultural
10 contexts without postural management equipment more commonplace in UK. The two-
11 dimensional video images were made by different people, selecting camera angles and
12 views that were thought to capture information required; in naturalistic settings, therapists
13 would have access to a greater range of information to classify young children's functional
14 eating and drinking ability. Better knowledge of a child's eating and drinking and/or
15 classifications made in person may lead to higher reliability than we found using videos but
16 this requires evaluation. The reliability of Mini-EDACS requires further study, including
17 comparisons between use by parents and health professionals.

18

19 Mini-EDACS extends the age range of EDACS, within the growing family of classification
20 systems (GMFCS, MACS, CFCS) describing functional performance of people with CP. Mini-
21 EDACS is designed for use by parents and/or professionals, and could facilitate working in
22 partnership, and enable more robust clinical and population-based research.

23

24 **CONCLUSION**

25 Mini-EDACS describes 5 distinct levels of eating and drinking ability for children with CP
26 aged 18 to 36 months. Use of Mini-EDACS by parents and professionals enables systematic
27 sharing of information about children's abilities. EDACS, with expanded descriptions of
28 function in Mini-EDACS, can facilitate working in partnership with families across the
29 lifespan. Mini-EDACS will broaden the focus of population-based research.

30

31 **ACKNOWLEDGEMENTS**

1 This article presents independent research funded by Nutricia Advanced Medical Nutrition
2 UK. The views expressed in this publication are those of the authors and not necessarily
3 those of Nutricia Advanced Medical Nutrition UK, the NHS, or the Department of Health. We
4 thank all those who chose to participate in this study; a list of Delphi Survey participants can
5 be found in Appendix I. We thank all our collaborators for their invaluable contributions: in
6 particular, we thank Jessica Rios, Anna Cavallini and Jessica Baskerville. We thank the
7 children and families from: Sussex in UK; Nuevo Amanecer in Mexico; Kekeli Ghana,
8 Multikids Africa, and Special Mothers Project in Ghana; and Centro In Equilibrio Brianza in
9 Italy.

10 **Bibliography**

11

- [1] P. Rosenbaum, N. Paneth, A. Leviton, M. Goldstein, M. Bax, D. Damiano and et al., "A report: the definition and classification of cerebral palsy," *Developmental Medicine & Child Neurology*, vol. 109, pp. 8-14, 2007.
- [2] H. Cass, C. Wallis, M. Ryan, S. Reilly and K. McHugh, "Assessing pulmonary consequences of dysphagia in children with neurological disabilities: when to intervene?," *Developmental Medicine & Child Neurology*, vol. 47, no. 5, pp. 347-52, 2005.
- [3] K. Weir, S. McMahon, L. Barry, I. B. Masters and A. B. Chang, "Clinical signs and symptoms of oropharyngeal aspiration and dysphagia in children.," *European Respiratory Journal*, vol. 33, no. 1, pp. 604-11, 2009.
- [4] E. Fung, L. Samson-Fang, V. Stallings, M. Conaway, G. Liptak, R. Henderson and et al., "Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy.," *Journal of the American Dietetic Association*, vol. 102, no. 3, pp. 361-73, 2002.
- [5] P. Sullivan, E. Juszczak, B. Lambert, M. Rose, M. Ford-Adams and A. Johnson, "Impact of feeding problems on nutritional intake and growth: Oxford Feeding Study II.," *Developmental Medicine & Child Neurology.*, vol. 44, no. 7, pp. 461-7, 2002.
- [6] S. Evans Morris and M. Dunn Klein, Evans Morris S, Dunn Klein M. Pre-feeding skills: a comprehensive resource for mealtime development. Second Edition., Academic Press, 2001.
- [7] G. Larnert and O. Ekberg, "Positioning improves the oral and pharyngeal swallowing function in children with cerebral palsy.," *Acta Paediatrica.*, vol. 84, pp. 689-92, 1995.

- [8] A. Eliasson, A. Ullenhag, U. Wahlstrom and L. Krumlinde-Sundholm, "Mini-MACS: development of the Manual Ability Classification System for children younger than 4 years of age with signs of cerebral palsy.," *Developmental Medicine & Child Neurology*, vol. 59, no. 1, pp. 72-78, 2017.
- [9] P. Rosenbaum, A. Eliasson, M. Hidecker and R. Palisano, "Rosenbaum P, Eliasson AC, Hidecker MJ, Palisano RJ. Classification in childhood disability: focusing on function in the 21st century.," *Journal Child Neurology*, vol. 29, no. 8, pp. 1036-45, 2014.
- [10] R. Palisano, P. Rosenbaum, D. Bartlett and M. Livingston, "Content validity of the expanded and revised Gross Motor Function Classification System.," *Developmental Medicine & Child Neurology*, vol. 50, no. 10, pp. 744-50, 2008.
- [11] D. Sellers, A. Mandy, L. Pennington, M. Hankins and C. Morris, "Sellers D, Mandy A, Pennington L, Hankins M, Morris C. Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy.," *Developmental Medicine & Child Neurology*, vol. 56, no. 3, pp. 245-51, 2014.
- [12] K. van Hulst, D. Snik, P. Jongerius, D. Sellers and C. Erasmus, "van Hulst, Karen et al. Reliability, Construct Validity and Usability of the Eating and Drinking Ability Classification System (EDACS) Among Dutch Children with Cerebral Palsy.," *Journal Pediatric Rehabilitation Medicine*, vol. 11, no. 2, pp. 115-124, 2018.
- [13] L. Tschirren, S. Bauer, C. Hanser, P. Marsico, D. Sellers and H. van Hedel, "The Eating and Drinking Ability Classification System: concurrent validity and reliability in children with cerebral palsy.," *Developmental Medicine & Child Neurology*, vol. 60, no. 6, pp. 611-617, 2018.
- [14] S. Hyun, Y. Yi and H. Shin, "Reliability and Validity of the Eating and Drinking Ability Classification System in Adults with Cerebral Palsy.," *Dysphagia*, vol. June, 2020.
- [15] H.-C. Chiu, K. Buckeridge, T.-A. Lee and D. Sellers, "Reliability and validity of the Eating and Drinking Ability Classification System (EDACS) for children with cerebral palsy in Taiwan," *Disability and Rehabilitation*, vol. online, no. August 16, pp. 1-7, 2021.
- [16] A.-C. Eliasson, L. Krumlinde-Sundholm, B. Rosblad, E. Beckung, M. Arner and A.-M. Ohrvall, "The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability.," *Developmental Medicine & Child Neurology*, vol. 48, pp. 549-554, 2006.
- [17] M. Hidecker, N. Paneth, P. Rosenbaum, R. Kent, J. Lillie, J. Eulenberg and et al. , "Developing and validating the Communication Function Classification System for individuals with cerebral palsy.," *Developmental Medicine & Child Neurology*, vol. 53, no. 8, pp. 704-10, 2011.
- [18] K. A. Benfer, K. A. Weir, K. L. Bell, R. S. Ware, P. S. Davies and R. Boyd, "Oro-pharyngeal dysphagia in preschool children with cerebral palsy: oral phase impairments.," *Research in Developmental Disabilities*, vol. 35, no. 12, pp. 3469-3481, 2014.

- [19] K. Benfer, K. Weir, K. Bell, R. Ware, P. Davies and R. Boyd, "Oropharyngeal dysphagia and gross motor skills in children with cerebral palsy.," *Pediatrics*, vol. 131, no. 5, pp. 1553-62, 2013.
- [20] A. Delbecq, A. Van de Ven and D. Gustafson, *Group techniques for program planning - a guide to Nominal Group and Delphi processes.*, Scott, Foresman and Co, 1975.
- [21] H. Linstone and M. Turoff, *The Delphi Method: Techniques and Applications.*, Available from: <http://is.njit.edu/pubs/delphibook>, 1975; published online 2002.
- [22] C. B. Terwee, S. D. Bot, M. R. De Boer, D. Van der Windt, D. L. Knol, J. Dekker and et al., "Quality criteria were proposed for measurement properties of health status questionnaires.," *Journal of clinical epidemiology*, vol. 60, no. 1, pp. 34-42, 2007.
- [23] I. Sinha, R. Smyth and P. Williamson, "Using the Delphi technique to determine which outcomes to measure in clinical trials: recommendations for the future based on a systematic review of existing studies.," *PLoS medicine*, vol. 8, no. 1, 2011.
- [24] J. A. Cohen, "A coefficient of agreement for nominal scales.," *Educational and Psychological Measurement.*, vol. 20, pp. 37-46, 1960.
- [25] J. Landis and G. Koch, "The measurement of agreement for categorical data.," *Biometrics*, vol. 33, pp. 159-74, 1977.
- [26] D. Streiner and G. Norman, *Health Measurement Scales: a practical guide to their development and use.* 4th Edition., Oxford University Press, 2008.
- [27] R. Fitzpatrick, C. Davey, M. Buxton and D. Jones, "Evaluating patient-based outcome measures for use in clinical trials.," *Health Technology Assessment.*, vol. 2, no. 14, 1998.
- [28] D. Sellers, E. Bryant, A. Hunter, V. Campbell and C. Morris, "The Eating and Drinking Ability Classification System for cerebral palsy: a study of reliability and stability over time.," *Journal Pediatric Rehabilitation Medicine*, vol. 12, no. 2, pp. 123-131, 2019.
- [29] K. A. Benfer, K. A. Weir, K. L. Bell, P. S. Davies and R. Boyd, "Eating and Drinking Ability Classification System in a population-based sample of pre-school children with cerebral palsy.," *Developmental Medicine and Child Neurology*, vol. 59, pp. 647-654, 2017.
- [30] K. L. Bell, K. A. Benfer, R. S. Ware, T. A. Patrao, J. J. Garvey, J. C. Arvedson, R. Boyd, P. S. Davies and K. A. Weir, "Development and validation of a screening tool for feeding / swallowing difficulties and undernutrition in children with cerebral palsy.," *Developmental Medicine and Child Neurology*, vol. 61, pp. 1175-1181, 2019.
- [31] N. Gibson, A. M. Blackmore, A. B. Chang, M. S. Cooper, A. Jaffe, W.-R. Kong, K. Langdon, L. Moshovis, K. Pavleski and A. C. Wilson, "Prevention and management of respiratory disease in young people with cerebral palsy: a consensus statement.," *Developmental Medicine and Child Neurology*, vol. 63, pp. 172-182, 2021.

1

2

Figure 1: Eating and Drinking Ability Classification System Algorithm and General Headings Levels I to V

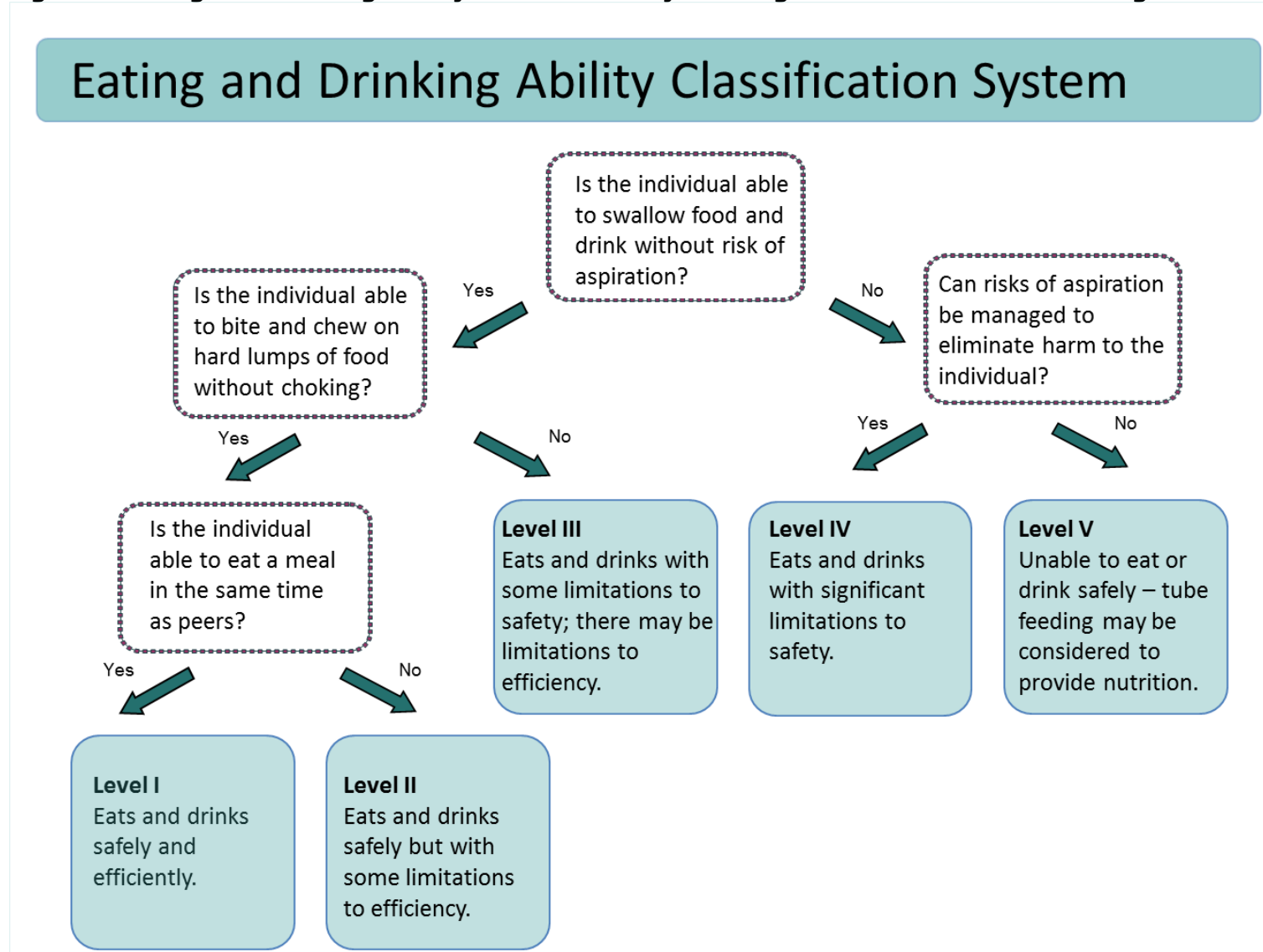


Table 1: Changes made to EDACS content to create Mini-EDACS. Deletions are indicated as strike-through, additions are indicated in **bold** typeface. Only content that has been modified to create Mini-EDACS is included here.

EDACS (>3 years)	Mini-EDACS (18-36 months)
PURPOSE	
This current version of EDACS describes the eating and drinking abilities of children with cerebral palsy from the age of 3 years to adulthood.	EDACS describes the eating and drinking abilities of children with cerebral palsy in two age bands: from age 18 months to 3 years and from 3 years to adulthood.
KEY FEATURES OF EATING AND DRINKING	
Aspiration occurs when food or fluid enters the lungs; this may be connected to limitations in co-ordinating breathing and swallowing, controlling food or fluid in the mouth or an impaired swallow reflex.	Aspiration occurs when food or fluid enters the lungs; this may be connected to limitations in co-ordinating breathing and swallowing, controlling food or fluid in the mouth or an impaired swallow reflex .
DESCRIPTIONS AND DISTINCTIONS BETWEEN THE LEVELS	
Level I: Eats and drinks safely and efficiently.	
May be challenged by some very firm bite and chew foods.	May be challenged by some very firm bite and effortful chew foods.
Moves food from one side of the mouth to the other; may close lips whilst chewing.	Moves food from one side of the mouth to the other; uses lips to take food into the mouth.
Drinks thin or thick fluids from range of cups with consecutive swallows, including through a straw.	Drinks thin or thick fluids from breast, infant bottle, valved, spouted or open cups with consecutive swallows.
May cough or gag for very challenging textures.	May cough or gag on new and / or challenging textures or sometimes when drinking thin fluid.
Retains most food or fluid in the mouth.	Retains most food or fluid in the mouth; may spit out non-preferred or unfamiliar food.
Clears food from most tooth surfaces and dislodges most foods from the sides of the mouth.	Clears food from most tooth surfaces and dislodges most foods from the sides of the mouth in response to sensation.
EDACS (>3 years)	Mini-EDACS (18-36 months)

Distinctions between levels I and II	
Compared with Level I, individuals in Level II will have some limitations with more challenging food textures. Eating and drinking will take longer for individuals at Level II.	Compared with Level I, individuals in Level II will have some limitations with more challenging food textures, especially biting and chewing . Eating and drinking will take longer for individuals at Level II.
Level II: Eats and drinks safely but with some limitations to efficiency.	
May chew with lips open.	May chew with wider than usual jaw movements, and with lips open.
Drinks thin or thick fluids from most cups with consecutive swallows; may drink through a straw.	Drinks thin or thick fluids from breast, infant bottle, valved or spouted cup with consecutive swallows; may find it more challenging to drink with consecutive swallows from open cup . May drink through a straw.
Coughs or gags on new or challenging textures, or when tiring.	Coughs or gags on new or challenging textures, or when mouth is overfull , or when tiring.
May sometimes cough if fluid is fast flowing or large quantity taken in the mouth.	May cough if fluid is fast flowing or large quantity taken into the mouth.
Loses small amounts of food or fluid especially challenging textures.	Loses small amounts of food or fluid especially challenging textures; may spit out challenging, non-preferred or unfamiliar foods .
Some foods will collect on some tooth surfaces and between cheeks and gums.	Some foods may collect on surface of tongue , some tooth surfaces and between cheeks and gums.
Level III: Eats and drinks with some limitations to safety; there may be limitations to efficiency.	
Eats puree and mashed food and may bite and chew some soft chew food textures.	Eats puree and mashed food and learning to bite and chew on some soft chew food textures.
It is challenging to move food from one side of the mouth to the other, to keep food in the mouth, and to bite and chew for safe eating.	Challenging to move food from one side of the mouth to the other, to keep food in the mouth, and to bite and chew for safe eating; tongue tends to move backwards and forwards in the mouth .
Eating and drinking performance is variable and depends upon overall physical ability, positioning or assistance given.	Eating and drinking performance is very variable and depends upon overall physical ability, tiredness , positioning or assistance given.
May drink from an open cup but drinking from cup with a lid or spout may be required to control the flow of fluid.	Drinks from infant bottle, valved or spouted cup which controls the flow of fluid; learning to drink from an open cup using small sips only or sometimes consecutive swallows .
EDACS (>3 years)	Mini-EDACS (18-36 months)

Specific food textures and positioning of food in mouth are required to reduce the risk of choking.	Specific food textures and /or positioning of food in mouth are required to reduce the risk of choking.
Food and fluid loss is likely and food will collect on tooth surfaces, roof of the mouth and between cheeks and gums.	Food and fluid loss is likely and food will collect on tooth surfaces, roof of the mouth and between cheeks and gums; may use tongue to push out challenging, unfamiliar and non-preferred foods.
Level IV: Eats and drinks with significant limitations to safety.	
May at times be difficult to co-ordinate swallowing and breathing when eating and drinking as shown by signs of aspiration.	May be difficult to co-ordinate swallowing and breathing when eating and drinking as shown by signs of aspiration.
It is challenging to control the movement of food and fluid in the mouth, to control mouth opening and closure, and to control swallowing, biting and chewing.	May find it difficult to control the movement of food and fluid in the mouth, to control mouth opening and closure, and to control swallowing, biting and chewing.
May swallow lumps whole.	May swallow lumps whole which may lead to choking.
May find it easier to drink thickened fluids than thin fluids; thickened fluids taken slowly and in small quantities from an open cup may increase control whilst drinking.	May find it easier to drink thickened fluids than thin fluids; thickened fluids taken slowly and in small quantities from an open cup may increase control whilst drinking. Consecutive swallows from infant bottle may be possible. Spouted cups may be required to reduce flow of fluid.
Will require specific food textures, fluid consistency, techniques, skilled carers, positioning and modified environment to reduce risks of aspiration and choking and increase efficiency.	Will require specific food textures, fluid consistency, techniques, skilled carers, positioning, careful pacing and modified environment to reduce risks of aspiration and choking and increase efficiency.
May tire whilst eating and mealtimes are likely to be prolonged.	May tire whilst eating and mealtimes will be prolonged.
Level V: Unable to eat or drink safely – tube feeding may be considered to provide nutrition.	
Ability to manage small tastes and flavours affected by positioning, personal factors and environmental features.	Ability to manage small tastes and flavours will be affected by positioning, personal factors and environmental features.
It is likely to be challenging to control mouth opening and tongue movement.	Difficulty with selectively controlling mouth opening and tongue movement.

Table 2: Demographics of children with CP in Inter-observer reliability studies (n=43)	
Age range	18 – 36 months
Mean age	28 months (SD 6.7)
Sex	30/43 males (70%)
Tube fed	3 (7%)*
#GMFCS Level:	
I	1 (2%)
II	4 (9%)
III	2 (4%)
IV	12 (28%)
V	24 (56%)
Country of residence:	
Ghana	11 (26%)
Italy	7 (16%)
Mexico	19 (44%)
England	6 (14%)
* all tube fed children were rated as GMFCS Level V	

#GMFCS = Gross Motor Function Classification System (ref)

Table 3: Reliability measures associated with use of Mini-EDACS by different observers – Speech and Language Therapists (SaLT) n=13

Inter-observer reliability Mini-EDACS Levels I-V SaLT1s vs SaLT2s: absolute agreement 58%; chance corrected agreement $k=0.43$; ICC 0.78 (95% CI 0.63-0.87)

SaLT 2	SaLT 1					Total
	I	II	III	IV	V	
I	4	1	0	0	0	5
II	1	1	1	1	0	4
III	1	2	4	2	0	9
IV	0	2	4	12	0	18
V	0	0	0	3	4	7
Total	6	6	9	18	4	43

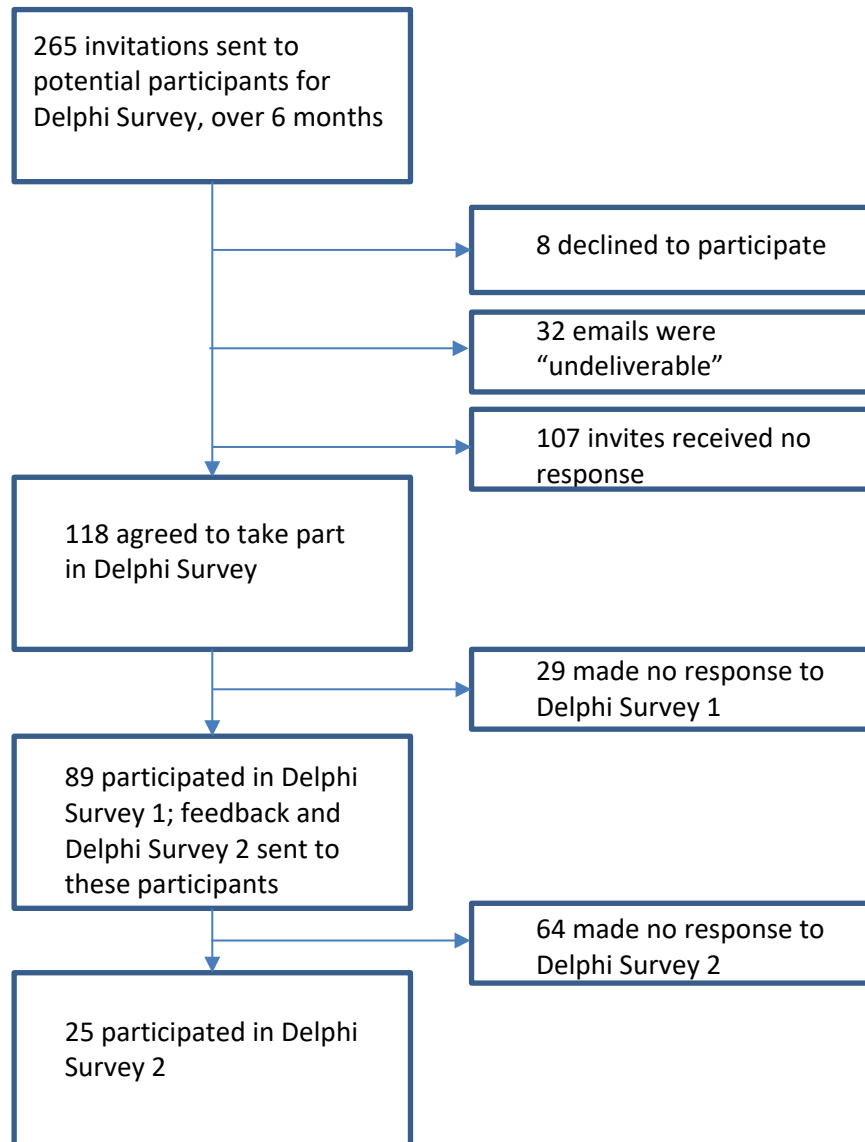
Inter-observer reliability Mini-EDACS Levels of assistance SaLT1 vs SaLT2: absolute agreement 86%; (k) kappa=0.62; (ICC) Intraclass Correlation Coefficient: 0.87 (95% CI 0.77-0.93)

SaLT2	SaLT 1			Total
	Independent	Requires assistance	Totally dependent	
Independent	6	0	0	6
Requires assistance	1	0	2	3
Totally dependent	0	3	31	34
Total	7	3	33	43

Table S1: Backgrounds of Delphi Survey Participants

Professional Backgrounds	Delphi Survey Participants N = 89
Parents of individuals with CP	2
Speech and Language Therapists / Pathologists	60
Community paediatricians	4
Paediatric Neuro developmental specialists	9
Neurologist	1
Dietitian	1
Occupational therapists	7
Physiotherapists	5
Researchers / epidemiologists	2
TOTAL BACKGROUNDS	91
Geographical region participants have experience of eating / drinking associated with CP	
Europe	66
Australasia	16
Americas	11
Africa	9
Asia	7
Middle East	3
Other (Brunei)	1
TOTAL	113
Years' experience with CP: Range 2 – 50 years; Mean 18.35 yrs (SD 10.2); Median 20yrs (IQR 15)	

Table S2: Supplementary mealtime questions answered by parents or carers	
1.	What is the most challenging food texture your child is able to eat? Please give some examples.
2.	Does your child take longer to eat than his / her peers? Please explain if you need to.
3.	Can your child drink through a straw?
4.	Do you need to change or modify food and / or drink to make it manageable for your child? Please give examples.
5.	Can your child chew soft lumps of food?
6.	Has your child experienced choking or aspiration events?
7.	Does eating and / or drinking cause harm to your child such as chest infections?
8.	Do you think it is easy for other people to give food and drink to your child? Please give examples.
9.	Is there anything else that you think it is important to tell us about your child's eating and / or drinking?

Figure S1: Number of participants at each stage of Mini-EDACS Delphi Survey

APPENDIX I

We are grateful to the many people who contributed to the development of the Mini-EDACS, some of whom chose to do so anonymously. The participants of the Delphi Survey who gave consent to the publication of their names were:

Rachel Quaid

Kirsty Jones

Judi Hibberd

Caroline Hartley

Laurel Allen

Arnab Seal

Jo Marks

Guro Andersen

Dinah Reddihough

Lesley Baker

Jenny Wood

Avinash Mishra

Anne Breaks

Helen Burnford

Karen Horridge

Virginia Knox

Marina Sloan

Rachel McDermott

Cecily Vale

Jo Jeffreson

Ellen Hoogland-Assen

Charlotte Wright

Alison Felton

Zarina Zahari

Speech and Language Therapists who participated in the Inter-rater reliability studies

included: Charlaine Kelsey, Jo Thursfield, Clare Bird, Georgia Pearson, Heather Lewes, Derinda Morgan, Saliah Malik, Laura Gozlan, Kate Jones, Amanda Harvey, Kay Hemmings, and Hannah Wasp.

Appendix II**Mini-EDACS Delphi Survey 1 Questions**

1. What is your background? Tick all that apply: [options] Parent of child with CP; Dietitian; Neurologist; Occupational Therapist; Physiotherapist; Paediatrician - Community; Paediatrician - Neuro-disability specialist; Speech and Language Therapist; Other (specify).
2. How many years' experience do you have with cerebral palsy?
3. Please indicate parts of the world where you have experience of the eating and drinking difficulties associated with cerebral palsy: [options] Africa; Americas; Asia; Australasia; Europe; Middle East; Other (specify)
4. Please describe what you consider to be the important features of eating and drinking for young children with cerebral palsy: [free text].
5. The **Purpose** of EDACS makes sense for young children with cerebral palsy aged 18 to 36 months: [Likert scale] 1. strongly disagree; 2. disagree; 3. slightly disagree; 4. neither agree nor disagree; 5. slightly agree; 6. agree; 7. strongly agree. [free text comments box]
6. The **Background** of EDACS is appropriate for young children with cerebral palsy aged 18 to 36 months: [Likert scale]; [free text comments box].
7. The **Key Features** of EDACS are appropriate for young children with cerebral palsy aged 18 to 36 months: [Likert Scale]; [free text comments box].
8. The **User Instructions** of EDACS are appropriate for young children with cerebral palsy aged 18 to 36 months: [Likert Scale]; [free text comments box].
9. The **Definitions - Section 1** of EDACS are appropriate for young children with cerebral palsy aged 18 to 36 months: [Likert Scale]; [free text comments box].
10. The **Definitions - Section 2** of EDACS are appropriate for young children with cerebral palsy aged 18 to 36 months: [Likert Scale]; [free text comments box].

11. The **General Headings** of EDACS are appropriate for young children with cerebral palsy aged 18 to 36 months: [Likert Scale]; [free text comments box].
12. The **Levels of Assistance Required** are appropriate for young children with cerebral palsy aged 18 to 36 months: [Likert Scale]; [free text comments box].
13. The description of **Level I** is clear for young children with cerebral palsy aged 18 to 36 months: [Likert Scale]; [free text comments box].
14. The description of **Level II** is clear for young children with cerebral palsy aged 18 to 36 months: [Likert Scale]; [free text comments box].
15. The description of **Level III** is clear for young children with cerebral palsy aged 18 to 36 months: [Likert Scale]; [free text comments box].
16. The description of **Level IV** is clear for young children with cerebral palsy aged 18 to 36 months: [Likert Scale]; [free text comments box].
17. The description of **Level V** is clear for young children with cerebral palsy aged 18 to 36 months: [Likert Scale]; [free text comments box].
18. The distinction between **Level I** and **Level II** is well defined: [Likert Scale]; [free text comments box].
19. The distinction between **Level II** and **Level III** is well defined: [Likert Scale]; [free text comments box].
20. The distinction between **Level III** and **Level IV** is well defined: [Likert Scale]; [free text comments box].
21. The distinction between **Level IV** and **Level V** is well defined: [Likert Scale]; [free text comments box].
22. Please add any further comments you have about Mini-EDACS here: [free text comments box].

Mini-EDACS Delphi Survey 2 Questions

1. Please indicate how much you agree with the changed wording of the description for **Level III** concerning tongue movement: [Likert Scale].
2. Please indicate how much you agree with the changed wording of the description for **Level III** concerning drinking: [Likert Scale].

APPENDIX III:

EDACS + Mini-EDACS



EATING AND DRINKING ABILITY
CLASSIFICATION SYSTEM



MiniEDACS

for children aged 18 – 36 months

PURPOSE

The purpose of the Eating and Drinking Ability Classification System (EDACS) is to classify how individuals with cerebral palsy eat and drink in everyday life using distinctions that are meaningful. EDACS provides a systematic way of describing an individual's eating and drinking in five different levels of ability.

The focus is on the functional activities of eating and drinking such as sucking, biting, chewing, swallowing and keeping food or fluid in the mouth. The different parts of the mouth include the lips, jaw, teeth, cheeks, tongue, palate and throat. The distinctions between the different levels in the EDACS are based upon functional ability, the need for adaptations to the texture of food and drink, the techniques used and some other features of the environment. It classifies overall performance in eating and drinking, which includes both motor and sensory elements.

The system provides a broad description of different levels of functional ability. The scale is ordinal. The distances between the levels are not equal and individuals with cerebral palsy will not be distributed equally across the levels.

EDACS is not an assessment tool to look in detail at the component parts of eating and drinking. It does not provide the comprehensive mealtime guidance required by some individuals with cerebral palsy to eat and drink safely and efficiently.

Changes to eating and drinking performance occur as someone grows as a result of physical development and experience. EDACS describes the eating and drinking abilities of children with cerebral palsy in two age bands: from age 18 months to 3 years and from 3 years to adulthood.

BACKGROUND

EDACS classifies an individual's usual performance rather than what can be done to the best of their ability. The focus of EDACS is to determine which level most accurately represents an individual's present abilities and limitations. An individual may eat and drink differently in different settings, be influenced by personal factors and the skill and familiarity of the carer, and other environmental features.

The way an individual balances, controls head movements and sits upright influences their oral skills whilst eating and drinking. Some individuals will require close attention to positioning in sitting, standing and lying, and adapted equipment to optimise their eating and drinking abilities. The manner and degree of postural management required by individuals will depend upon their gross motor abilities.

We encourage users of EDACS to be aware of how other factors associated with cerebral palsy can influence an individual's performance whilst eating or drinking. These might include seizures and disturbances to cognition, communication, sensation, vision and hearing, as well as behaviour. Illness, tiredness, pain or medication will also have an effect. A wide range of personal factors and social, emotional and behavioural issues can become associated with eating and drinking. Features of the environment may also have an influence such as a familiar or new carer, background or sudden noises, quality of lighting and sudden movements. If an individual requires assistance with eating and drinking, a highly significant feature will be the quality of the relationship between the individual and the carer, including how well they each communicate with the other.

Disturbances of the digestive system such as gastro-oesophageal reflux or constipation will have an impact upon appetite and interest in food.

KEY FEATURES OF EATING AND DRINKING

Key features of the process of eating and drinking are **safety** and **efficiency**.

Safety refers to the risks of **choking** and **aspiration** associated with eating and drinking.

Choking occurs when a piece of food becomes lodged in the airway; this may be connected to limitations in chewing and biting as well as co-ordinating the movement of food in the mouth with swallowing.

Aspiration occurs when food or fluid enters the lungs; this may be connected to limitations in co-ordinating breathing and swallowing, controlling food or fluid in the mouth or an impaired swallow. Some aspects of eating and drinking are impossible to observe, especially swallowing. Even if you know someone really well it is not always easy to notice the **signs of aspiration**; this is known as **silent aspiration**.

Aspiration may trigger respiratory illnesses and is potentially harmful. If aspiration is suspected, it is helpful to seek further assessment from a suitably qualified professional such as a speech and language therapist.

Efficiency refers to the length of time and effort required to eat or drink, as well as whether food or drink is kept in the mouth without loss. Limitations to the quality and speed of movement of the different parts of the mouth will affect how efficiently food and drink is consumed. The amount of effort required for eating and drinking will have an impact upon how quickly an individual tires during a meal.

The **efficiency** with which someone uses the parts of the mouth to eat and drink has an impact upon the amount of food and fluid they are able to consume. This is one of a number of factors that influence whether an individual is able to take in enough food and drink to grow and remain in good health. It is considered good practice to assess individual nutrition and hydration requirements and decide whether these are being met adequately.

USER INSTRUCTIONS

From the different descriptions given below, choose the level that best describes an individual's overall usual performance when eating and drinking.

To identify the level of eating and drinking ability of an individual with cerebral palsy, it is necessary to involve someone who knows that person well such as a parent or carer. Some aspects of eating and drinking are not possible to see, so it may be helpful to assign a level together with a professional who has knowledge about the necessary skills for safe and efficient eating and drinking.

In borderline cases the level of the EDACS which describes the greater level of limitation should be assigned.

Different degrees of assistance will be needed when eating or drinking depending upon age and the ability to bring food or drink to the mouth. The level of assistance required may change throughout life, beginning with the total dependence of the young infant. The EDACS level assigned to an individual is supplemented with an indication of whether an individual is **Independent** whilst eating and drinking, **Requires Assistance** in bringing food and drink to the mouth or is **Totally Dependent**.

DEFINITIONS

Age appropriate food textures refers to textures of food typically given to a particular age group (e.g. in some cultures, nuts and tough meats are not given to young children).

Aspiration is defined as the entry of material (e.g. food or fluid) into the airway or lungs below the vocal cords. This may occur when there is weak or uncoordinated movement of food or fluid from the mouth to the oesophagus whilst eating. This is usually accompanied by coughing, breathing changes and other signs of aspiration; the term **silent aspiration** is used if outward signs of aspiration such as coughing are not obvious when a person aspirates. Aspiration may cause harm by contributing to respiratory illness and chronic respiratory diseases.

Breathing changes might be noticed during eating or drinking which might suggest difficulty clearing food or fluid away from the airway and throat. The changes observed may be linked to the sound of the breathing (e.g. wheezy, rattly, noisy or wet) or may be linked to changes to the way someone breathes (e.g. changes to the rate of breathing or laboured, effortful breathing).

Choking is the partial or complete blocking of the airway due to a foreign object becoming lodged in the throat or windpipe. The blockage may be relieved by coughing. If not, the individual will require assistance (e.g. UK Resuscitation Council recommendations).

Fluid consistency refers to how thick or thin a fluid is. Fluid consistency changes the speed at which fluid moves. It may mean the difference between fluid being swallowed safely and fluid entering the airway or lungs. Thin fluids, such as water, are fast flowing and require quick co-ordination of the movements of swallowing and breathing. Smooth thicker fluids flow more slowly and may be recommended to individuals with slower movements during swallowing in order to reduce the risk of fluid entering the airway or lungs, and/or to reduce loss of fluid from the lips. Thick fluids may be prepared by using diluted yoghurts or thick soups; thin fluids may be thickened using commercially available thickening agents.

Food textures will affect how easy it is to eat something. Different foods have a range of qualities requiring different degrees of effort, strength and co-ordination to eat. Features to consider include the shape and size of the food, how hard it is to bite and chew the food into small enough pieces ready for swallowing and what happens once bitten – foods can dissolve, splinter, crumble or lump together. Most foods can be modified to change the texture to one that is easier to manage (e.g. mixed textures can be mashed down, tough meats blended, large pieces cut into smaller pieces). Some individuals may need to avoid certain foods if they cannot be modified.

EDACS refers to:

- **Firm bite and effortful chew textures** which are the most challenging to eat (e.g. tough meats, molluscs, hard nuts, crunchy fibrous fruit and vegetables).
- **Mixed textures** where different food textures and fluid consistencies are combined (e.g. lumps of food in a thin soup, watery puree which separates into fluid and food, meat and salad sandwich).
- **Slippery textures** of food are particularly challenging to control in the mouth and eat safely (e.g. melon or grapes).
- **Sticky foods** can cause problems if an individual has difficulty clearing the mouth (e.g. nut butters, halva, tahini and toffee).
- **Hard chew textures** require effort, strength and co-ordination to eat (e.g. raw fruit and vegetables, meat, crackers, crusty bread).
- **Soft chew textures** require less effort, strength and co-ordination to eat (e.g. well cooked non fibrous vegetables, very ripe peeled fruit without seeds, well cooked pasta and soft cake).
- **Well mashed foods** require very little chewing (e.g. well cooked meat mashed with potato or well cooked vegetables, well cooked pasta or cake mashed with cream).
- **Puree** has a smooth uniform consistency which requires no chewing.
- **Tastes or Flavours** may be offered when eating or drinking is not safe. **Tastes** are a minute amount of puree to be swallowed. A **flavour** has nothing of substance to be swallowed (e.g. what remains on a finger dipped in fluid with the drips shaken off).

Gastrostomy or PEG (Percutaneous Endoscopic Gastrostomy) is a surgical opening into the stomach usually for the long term placement of a feeding tube.

Oesophagus is the name of the tube which connects the mouth and back of the throat to the stomach.

Postural Management Programme is a planned approach encompassing all activities and interventions which impact on an individual's posture and function. Programmes are tailored specifically for each child and may include special seating, night time support, standing supports, orthotics, active exercise, surgery and individual therapy sessions.

Signs of Aspiration are clinical observations that have been linked to Aspiration: coughing, wet sounding voice, breathing changes (sound of breathing as well as the rate and manner of breathing), changes in skin colour, whole body reactions, eye widening or watering, or panic reactions evident in facial expression.

Silent Aspiration is the term given when aspiration takes place but outward signs of aspiration such as coughing do not occur. Other Signs of Aspiration such as eye widening or watering, or panic reactions evident in facial expression may be observed.

Suction is when secretions are cleared from an individual's airway through the use of a specifically designed suction pump.

Tube Feeding is when a tube is passed through the nose (or mouth) or through a surgical incision into the body (e.g. naso-gastric tube or gastrostomy). Medication, fluid or a liquid feed may be passed down this tube.

GENERAL HEADINGS

- Level I** Eats and drinks safely and efficiently.
- Level II** Eats and drinks safely but with some limitations to efficiency.
- Level III** Eats and drinks with some limitations to safety; there may be limitations to efficiency.
- Level IV** Eats and drinks with significant limitations to safety.
- Level V** Unable to eat or drink safely – tube feeding may be considered to provide nutrition.

Fuller descriptions of the levels are given below along with distinctions between the levels. These are to assist in determining the level that most closely resembles an individual's current eating and drinking ability.

LEVEL OF ASSISTANCE REQUIRED

An individual's eating and drinking ability will be expressed as a level I-V followed by an indication of the degree of help needed at mealtimes. For example, a child who is able to eat safely with some limitations to efficiency and requires assistance in loading the spoon or steadying a cup would be **EDACS Level II Requires Assistance (RA)**; a child who has an unsafe swallow and is able to bring food and drink to the mouth would be **EDACS Level V Independent (Ind)**. The level of assistance

Independent (Ind) indicates that individuals are able to bring food and drink to their own mouth without any assistance. It does not indicate that individuals are able to modify food to the required texture for safe and / or efficient eating and drinking. It also does not indicate that individuals are able to sit independently.

Requires Assistance (RA) indicates that an individual needs help to bring food or drink to the mouth, either from another person or through the use of adapted equipment. Help may be needed loading the spoon, placing food in the hand or guiding the individual's hand to the mouth, holding a cup steadily, providing close supervision or verbal prompts.

Totally Dependent (TD) indicates that an individual is totally dependent upon another to bring food or drink to the mouth.

DESCRIPTIONS OF DIFFERENT LEVELS

The **Orange** section describes the different levels for children aged 18-36 months.

The **Green** section describes the different levels from age 3 years.

Level I 18 – 36 months • Eats and drinks safely and efficiently

MiniEDACS

Eats a wide range of different texture foods that are age appropriate.

May be challenged by some firm bite and effortful chew foods.

Moves food from one side of the mouth to the other

Uses lips to take food into the mouth.

Drinks thin or thick fluids from breast, infant bottle, valved, spouted or open cups with consecutive swallows.

May cough or gag on new and/or challenging textures or sometimes when drinking thin fluid.

Eats and drinks at a similar speed to peers.

Retains most food or fluid in the mouth; may spit out non-preferred or unfamiliar food.

Clears food from most tooth surfaces and dislodges most foods from the sides of the mouth in response to sensation.

Distinctions between I and II: Compared with Level I, individuals in Level II will have some limitations with more challenging food textures, especially biting and chewing. Eating and drinking will take longer for individuals at Level II.

Level II 18 – 36 months • Eats and drinks safely but with some limitations to efficiency

MiniEDACS

Eats a range of food textures that are age appropriate.

Challenged by some firm bite, effortful chew, mixed and sticky textures.

Moves food slowly from one side of the mouth to the other using the tongue.

May chew with wider than usual jaw movements, and with lips open.

Drinks thin or thick fluids from infant bottle, valved or spouted cup with consecutive swallows; may find it more challenging to drink with consecutive swallows from open cup.

Coughs or gags on new or challenging textures, or when mouth is overfull, or when tiring.

May cough if fluid is fast flowing or large quantity taken into the mouth.

May tire if textures challenging and mealtimes will take longer than for peers.

Loses small amounts of food or fluid especially challenging textures; may spit out challenging, non-preferred or unfamiliar foods.

Some foods may collect on surface of tongue, some tooth surfaces and between cheeks and gums.

Distinctions between II and III: Individuals in Level II manage most age appropriate food textures and drink with some slight modifications. Individuals at Level III will need more food textures to be modified in order to reduce risk of choking.

Level III 18 – 36 months • Eats and drinks with some limitations to safety; there may be limitations to efficiency

MiniEDACS

Eats puree and mashed food, and learning to bite and chew on some soft chew food textures.

Challenged by large lumps, firm bite and effortful chew textures which may lead to choking and reduced efficiency.

Challenging to move food from one side of the mouth to the other, to keep food in the mouth, and to bite and chew for safe eating; tongue tends to move backwards and forwards in the mouth.

Eating and drinking performance is very variable and depends upon overall physical ability, tiredness, positioning or assistance given.

Drinks from infant bottle, valved or spouted cup which controls the flow of fluid; learning to drink from an open cup using small sips only or sometimes consecutive swallows.

May drink thickened fluids more easily than thin and may need time between sips.

May choose to drink only in certain situations such as with a trusted carer or with no distractions.

Specific food textures and/or positioning of food in mouth are required to reduce the risk of choking.

May cough or aspirate if fluid is fast flowing or large quantity taken in the mouth.

May tire whilst eating if food requires chewing and mealtimes will be prolonged.

Food and fluid loss is likely and food will collect on tooth surfaces, roof of the mouth and between cheeks and gums; may use tongue to push out challenging, unfamiliar and non-preferred foods.

Distinctions between III and IV: Individuals at Level III manage to chew soft lumps. Individuals at Level IV will need close attention given to a number of different factors to swallow food and drink safely because of the significant aspiration and choking risk.

Level IV 18 – 36 months • Eats and drinks with significant limitations to safety

MiniEDACS

Eats smooth purees or well mashed food.

Challenged by food that requires chewing; choking may occur if lumps are eaten.

May be difficult to co-ordinate swallowing and breathing when eating and drinking as shown by signs of aspiration.

May find it difficult to control the movement of food and fluid in the mouth, to control mouth opening and closure, and to control swallowing, biting and chewing.

May swallow lumps whole which may lead to choking.

May find it easier to drink thickened fluids than thin fluids; thickened fluids taken slowly and in small quantities from an open cup may increase control whilst drinking. Consecutive swallows from infant bottle may be possible. Spouted cups may be required to reduce flow of fluid.

May choose not to drink fluids or to drink only in certain situations such as with trusted carer.

Likely to need time between mouthfuls to swallow repeatedly before continuing.

Will require specific food textures, fluid consistency, techniques, skilled carers, positioning, careful pacing and modified environment to reduce risks of aspiration and choking and increase efficiency.

May tire whilst eating and mealtimes will be prolonged.

Significant food and fluid loss from the mouth.

Food may become stuck on tooth surfaces, roof of the mouth and between teeth and gums.

Supplementary tube feeding may be considered.

Distinctions between IV and V: Individuals at Level IV are able to swallow safely only if close attention is given to food texture and fluid consistency as well as the way in which food or drink is offered. Individuals at Level V cannot swallow safely so that taking food or drink in to their mouths will cause harm.

Level V 18 – 36 months • Unable to eat or drink safely – tube feeding may be considered to provide nutrition

May manage very small tastes or flavours.

Ability to manage small tastes and flavours affected by positioning, personal factors and environmental features.

Unable to swallow food or drink safely due to limitations to the range and co-ordination of movement for swallowing and breathing.

Difficulty controlling mouth opening and tongue movement.

Aspiration and choking are very likely.

Harm from aspiration is evident.

May require suction or medication to keep airway clear of secretions.

Alternative means of providing nutrition such as tube feeding may be considered

Level I 3 years + • Eats and drinks safely and efficiently

- Eats a wide range of different texture foods that are age appropriate.
- May be challenged by some very firm bite and chew foods.
- Moves food from one side of the mouth to the other; may close lips whilst chewing.
- Drinks thin or thick fluids from range of cups with consecutive swallows, including through a straw.
- May cough or gag for very challenging textures.
- Eats and drinks at a similar speed to peers.
- Retains most food or fluid in the mouth.
- Clears food from most tooth surfaces and dislodges most foods from the sides of the mouth.

Distinctions between I and II: Compared with Level I, individuals in Level II will have some limitations with more challenging food textures. Eating and drinking will take longer for individuals at Level II.

Level II 3 years + • Eats and drinks safely but with some limitations to efficiency

EDACS

- Eats a range of food textures that are age appropriate.
- Challenged by some firm bite, effortful chew, mixed and sticky textures.
- Moves food slowly from one side of the mouth to the other using the tongue.
- May chew with lips open.
- Drinks thin or thick fluids from most cups with consecutive swallows; may drink through a straw.
- Coughs or gags on new or challenging textures or when tiring.
- May sometimes cough if fluid is fast flowing or large quantity taken in the mouth.
- May tire if textures challenging and mealtimes will take longer than for peers.
- Loses small amounts of food or fluid especially challenging textures.
- Some foods will collect on some tooth surfaces and between cheeks and gums.

Distinctions between II and III: Individuals in Level II manage most age appropriate food textures and drink with some slight modifications. Individuals at Level III will need more food textures to be modified in order to reduce risk of choking.

Level III 3 years + • Eats and drinks with some limitations to safety; there may be limitations to efficiency

EDACS

- Eats puree and mashed food and may bite and chew some soft chew food textures.
- Challenged by large lumps, firm bite and effortful chew textures which may lead to choking and reduced efficiency.
- It is challenging to move food from one side of the mouth to the other, to keep food in the mouth, and to bite and chew for safe eating.
- Eating and drinking performance is variable and depends upon overall physical ability, positioning or assistance given.
- May drink from an open cup but drinking from cup with a lid or spout may be required to control the flow of fluid.
- May drink thickened fluids more easily than thin and may need time between sips.
- May choose to drink only in certain situations such as with a trusted carer or with no distractions.
- Specific food textures and positioning of food in mouth are required to reduce the risk of choking.
- May cough or aspirate if fluid is fast flowing or large quantity taken in the mouth.
- May tire whilst eating if food requires chewing and mealtimes will be prolonged.
- Food and fluid loss is likely and food will collect on tooth surfaces, roof of the mouth and between cheeks and gums.

Distinctions between III and IV: Individuals at Level III manage to chew soft lumps. Individuals at Level IV will need close attention given to a number of different factors to swallow food and drink safely because of the significant aspiration and choking risk.

Level IV 3 Years + • Eats and drinks with significant limitations to safety

- Eats smooth purees or well mashed food.
- Challenged by food that requires chewing; choking may occur if lumps are eaten.
- May at times be difficult to co-ordinate swallowing and breathing when eating and drinking as shown by signs of aspiration.
- It is challenging to control the movement of food and fluid in the mouth, to control mouth opening and closure, and to control swallowing, biting and chewing.
- May swallow lumps whole.
- May find it easier to drink thickened fluids than thin fluids; thickened fluids taken slowly and in small quantities from an open cup may increase control whilst drinking.
- May choose not to drink fluids or to drink only in certain situations such as with trusted carer.
- Likely to need time between mouthfuls to swallow repeatedly before continuing.
- Will require specific food textures, fluid consistency, techniques, skilled carers, positioning and modified environment to reduce risks of aspiration and choking and increase efficiency.
- May tire whilst eating and mealtimes are likely to be prolonged.
- Significant food and fluid loss from the mouth.
- Food may become stuck on tooth surfaces, roof of the mouth and between teeth and gums.
- Supplementary tube feeding may be considered.

Distinctions between IV and V: Individuals at Level IV are able to swallow safely only if close attention is given to food texture and fluid consistency as well as the way in which food or drink is offered. Individuals at Level V cannot swallow safely so that taking food or drink in to their mouths will cause harm.

Level V 3 Years + • Unable to eat or drink safely – tube feeding may be considered to provide nutrition

EDACS

- May manage very small tastes or flavours.
- Ability to manage small tastes and flavours will be affected by positioning, personal factors and environmental features.
- Unable to swallow food or drink safely due to limitations to the range and co-ordination of movement for swallowing and breathing.
- It is likely to be challenging to control mouth opening and tongue movement.
- Aspiration and choking are very likely.
- Harm from aspiration is evident.
- May require suction or medication to keep airway clear of secretions.
- Alternative means of providing nutrition such as tube feeding may be considered

Mini-EDACS Project Team

Diane Sellers, Lindsay Pennington, Kath Benfer, Kelly Weir, Elizabeth Bryant and Christopher Morris.

Mini-EDACS Funding

The Mini-EDACS is the product of an independent research project funded for 18 months from May 2017 to November 2018 by Nutricia Advanced Medical Nutrition. The views expressed are those of the authors and not necessarily those of the NHS or Nutricia Advanced Medical Nutrition.

EDACS Project Team

Diane Sellers, Michael Carter, Sarah Ford, Matthew Hankins, Anne Mandy, Christopher Morris, Lindsay Pennington, Terry Pountney.

Funding

The Eating and Drinking Ability Classification System is the product of an independent research project funded for three years from April 2010 to March 2013 by the National Institute of Health Research, under its Research for Patient Benefit Programme (Grant Reference Number PB-PG-1208-18144). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

Reference

Sellers D, Mandy A, Pennington L, Hankins M and Morris C (2013). Development and reliability of a system to classify eating and drinking ability of people with cerebral palsy. *Developmental Medicine and Child Neurology*. 15/3;p245-251. DOI: 10.1111/dmcn12352.

Contact

Chailey Clinical Services
Beggars Wood Road
North Chailey
Nr Lewes
BN8 4JN
UK

Tel: +44 1825 724720

Email: SC-TR.edacs@nhs.net

Website: www.edacs.org

