

1 The Eating and Drinking Ability Classification System for cerebral palsy: a study of reliability and
2 stability over time.

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13 **Abstract:**

14 **Aim:**

15 This study evaluated the inter-observer reliability and stability over time of the Eating and Drinking
16 Ability Classification System (EDACS) for children and young people with cerebral palsy (CP).

17 **Method:**

18 Case-records for 97 children with CP were examined to collect retrospective data about eating and
19 drinking abilities, at four time-points, minimum 2 years between each time-point. Sex, Gross Motor
20 Function Classification System (GMFCS) level, presence of feeding tube and orthopaedic issues were
21 recorded from case-records. One speech and language therapist (SaLT1) classified eating and
22 drinking ability using EDACS for all cases at all time-points; SaLT2 assigned EDACS levels for 50 cases
23 at time-point 1; SaLT3 assigned EDACS levels for 24 cases at all time-points. Inter-observer reliability
24 and stability over time were assessed using Intraclass Correlation Coefficient (ICC). Associations
25 between EDACS levels and functioning recorded with other Functional Classification Systems (FCSs)
26 were calculated using Kendall's tau (τ).

27 **Results:**

28 Out of 97 children, 48 were male, 48 had feeding tubes, and 83 had orthopaedic issues. ICC for
29 EDACS levels recorded by SaLT1 across all time-points was 0.97 (95%CI 0.96-0.98); changes in EDACS
30 levels occurred infrequently and never by more than one level. ICC between SaLT1 and SaLT2 at
31 time-point 1 was 0.8 (95%CI 0.67-0.89); ICC between SaLT1 and SaLT3 across all time-points was 0.95
32 (95%CI 0.92-0.98). Association between GMFCS and EDACS was moderate ($\tau = 0.58$).

33 **Interpretation:**

34 Retrospective use of EDACS to classify children’s eating and drinking abilities appears reliable; EDACS
35 appeared stable over 6 or more years in 86% of the cases.

36 **Keywords:**

37 Cerebral palsy, eating, drinking, EDACS, lifecourse

38

39 **Background:**

40 In the field of developmental disability it is well known that children and young people with the
41 same condition, such as cerebral palsy (CP), vary considerably in their functional abilities. In recent
42 years there has been a recognition of the utility of functional classification systems (FCS) which
43 provide far more detail than a diagnostic label alone¹. The oldest and most widely used of these FCS
44 is the Gross Motor Function Classification System (GMFCS²); others have been developed to describe
45 manual ability (Manual Ability Classification System MACS³), communication function
46 (Communication Function Classification System CFCS⁴) and speech production (Viking Speech Scale
47 VSS⁵). Each of these FCS describe function using distinct levels which are meaningful in daily life,
48 replacing poorly defined, value laden terms such as mild, moderate and severe. The GMFCS, MACS
49 and CFCS describe the full range of ability in 5 levels whereas the Viking Speech Scale uses 4 levels.
50 See Table 1 for summary headings for each of the FCS.

51 FCS are considered to be useful in both clinical and research contexts because they can facilitate
52 clear communication and planning at local and national level. Different FCS levels can be used to
53 consider different clinical management options and enable clear reporting of research findings
54 contributing to the clinical evidence base. In some cases FCS enable prediction of future outcomes
55 through the stability of the assigned FCS level¹.

56 The contribution of eating and drinking difficulties to poor respiratory health has been well
57 documented^{6,7,8,9}. Eating and drinking difficulties have also been associated with limited growth and
58 poor health because of compromised nutritional intake^{10,11} and in some instances can lead to
59 premature death¹². Prevalence figures for eating and drinking difficulties for children with CP vary
60 widely depending upon definitions and measures used¹³. Prevalence rates include: 21% with
61 “swallowing and chewing difficulties”¹⁴; 40% with “difficulties with eating”¹⁵; 55% with limitations to
62 “chewing and swallowing”¹⁶; and 85% with “oro-pharyngeal dysphagia” assessed using two
63 standardised measures¹⁷. A systematic review of ordinal scales used to measure eating and drinking
64 ability of people with CP¹⁸ identified 15 different scales: 13/15 were for clinician or researcher use
65 only; 8/15 used the terms mild, moderate and severe with varying definitions to describe different
66 aspects of eating and drinking impairment; none met recommended psychometric quality
67 standards⁴¹. The review clearly identified the need for a new classification system of eating and
68 drinking ability¹⁸.

69 The Eating and Drinking Ability Classification System (EDACS) has recently been added to this group
70 of FCS^{19,1}. EDACS describes the full range of eating and drinking ability of children and young people
71 with CP from age 3 years in five distinct levels, using the key features of safety and efficiency. EDACS
72 focuses on a person's usual performance of biting, chewing, drinking, and swallowing and the co-
73 ordination of these with respiration. Descriptions of different levels of ability include details of food

74 and fluid textures that can be managed without choking or aspiration (entry of food or fluid into the
75 lungs). Descriptions also include the extent to which food and fluid are retained in the mouth and
76 speed and range of movement brought to the task. Like the other FCSs, EDACS has been shown to be
77 valid and reliable for children and young people with CP¹⁹. Studies have demonstrated that EDACS
78 meets quality standards for inter-observer reliability between health professionals, and between
79 parents and health professionals^{19,20,21,22}. High intra-rater-reliability²⁰ and strong construct
80 validity^{21,22} have also been demonstrated.

81 Each FCS provides broad categorical descriptions of function such that a level assigned to a child with
82 CP is unlikely to change over time; if change does happen it is likely to be by just one level¹. Ohrvall
83 et al.²³ stated that it is necessary to consider the extent to which stability is influenced by potential
84 changes in ability or whether it is due to inconsistency in use of the tool by different or the same
85 raters. Research evaluating the GMFCS and MACS has demonstrated the stability of function over
86 time in retrospective²⁴ and prospective studies^{23,25,26}.

87 There is limited evidence from longitudinal observations of the eating and drinking abilities of people
88 with CP, hampered by the lack of consensus concerning measurement tools²⁷. There is no clear
89 understanding of the natural history of eating and drinking development in CP and no context within
90 which to assess the impact of interventions to improve function. Currently, parents and health
91 professionals make significant and emotive clinical decisions such as use of tube feeding without
92 evidence of the stability of children and young people's eating and drinking ability. Conflict can arise
93 between parents and health professionals when engaged in decision making linked to children's
94 limitations in eating and drinking abilities^{28,29,30}. Some parents resist proactive recommendations by
95 the clinical team to use alternative and supplementary tube feeding for their child at a young age;
96 this can result in limited growth and compromised health associated with chronic malnutrition for
97 their child's lifetime¹⁰. The EDACS is a measurement tool that parents are able to understand,
98 recognising their own child's eating and drinking abilities within the levels¹⁹. Discussions with parents
99 could be enhanced with a clear statement about a child's eating and drinking ability using EDACS
100 together with research evidence about how likely it is that this level will change in the future.

101 The use of EDACS in clinical and research contexts will be supported by evidence concerning the
102 stability of eating and drinking function measured by EDACS throughout childhood. The purpose of
103 this study was to 1) to measure the inter-observer reliability of EDACS applied retrospectively using
104 case notes, 2) to assess the stability over time of a child's EDACS level and 3) to compare EDACS
105 levels with other areas of function measured by other FCSs.

106 **Method:**

107 This study was carried out as a retrospective case note review, following a similar study design
108 employed in retrospective examination of GMFCS levels from case notes by Wood and Rosenbaum²⁴.
109 The study took place at a centre providing specialist care to children and young people with complex
110 neuro-disability, part of a community NHS trust in the UK. The multi-professional nutrition team
111 manage the nutritional and hydrational intake of children with complex neuro-disability; team
112 members include dietitian, neuro-developmental paediatrician, speech and language therapist and
113 specialist children's nurse. Recommendations for safe and efficient mealtime support are provided
114 for parents and care staff within a prescribed format in order to optimise nutrition and mealtime

115 experiences. Electronic case records are available which detail the overall function and eating and
116 drinking ability of children with CP dating from 2001.

117 NHS Health Research Authority approval was conferred by London – Camden and Kings Cross
118 Research Ethics Committee REC reference: 16/LO/0344 IRAS Project ID: 197498.

119 **Identification of Cases:**

120 Children were included in the study if a diagnosis of CP was confirmed by a neuro-developmental
121 paediatrician. Children had to have had at least 6 years contact with the specialist centre from age 3
122 years and above, between the years 2001 and 2016. Contact may not have been over consecutive
123 years. The 15 year time frame was pragmatically determined because key documents from case
124 records stored on computer databases could be routinely accessed from 2001. Data were collected
125 for each child at four time-points (TP) with a minimum of 2 years between each TP. The selected TPs
126 extend across the period of time that children accessed services, including TPs before and after
127 adolescence. Children were excluded from the study if they had less than 6 years contact or where
128 there were insufficient data on their eating and drinking abilities.

129 **Data extraction and coding:**

130 Case notes were used to record the following information: sex, CP type following Surveillance of
131 Cerebral Palsy in Europe classification tree³¹, GMFCS level at each TP, presence of feeding tube and
132 age at which tube insertion was carried out, presence of seizures, gastro-oesophageal reflux and
133 orthopaedic issues. Case notes include annual medical reports which routinely summarise diagnosis,
134 present and past problems, medication, investigations and interventions. Annual therapy reports are
135 produced for each child which include descriptions of gross motor and communication function,
136 manual and eating and drinking ability. The following FCS were used to describe different aspects of
137 children's function: Manual Ability Classification System³, Communication Function Classification
138 System⁴ and Viking Speech Scale⁵ at TP1. See **Table 1** for summary descriptions of levels for GMFCS²,
139 MACS³, CFCS⁴ and Viking Speech Scale⁵.

140 The lead author (DS) extracted case note information. DS conferred with neuro-developmental
141 paediatrician (VC) who checked CP diagnosis and clinical summaries for each child.

142 **Eating and Drinking Ability Classification System Levels:**

143 The most detailed clinical records of eating and drinking function for each child were selected by the
144 lead author (DS) across 4 Time Points. Clinical records were used by 3 specialist speech and language
145 therapists (SaLTs) to identify the EDACS level which best described that child's eating and drinking
146 ability at the first time-point (TP1) and across all time-points (TP1, TP2, TP3, TP4). The summary
147 descriptions for each EDACS level are given in **Table 2**.

148 EDACS was published in 2014 and not routinely included in case records at the specialist centre until
149 2015. Each of the 5 levels of EDACS systematically describes the safety and efficiency of someone's
150 eating and drinking ability using similar content to that contained in case records. Retrospective use
151 of EDACS involved the conversion of qualitative clinical data into ordinal scale data. Clinical reports,
152 case notes and annual mealtime guidance sheets produced following NHS National Patient Safety
153 Agency³² recommendations contain information about safety of swallowing, chewing ability, risk of

154 aspiration or choking, recommended food textures and fluid consistencies, positioning, assistance
155 required at mealtimes and required techniques for each child. The reliability of classifying function
156 using EDACS using clinical data as source material was tested in two ways. The lead author and first
157 SaLT1 (DS) assigned EDACS levels for all cases across all time points. The second SaLT2 assigned
158 EDACS levels for 51% of randomly selected cases at TP1. The third SaLT3 assigned EDACS levels for
159 25% of randomly selected cases across each of the time points. Reliability testing followed guidance
160 set out in international quality standards⁴¹. The reliability of the use of EDACS by pairs of SaLTs was
161 examined using two way contingency tables to consider percentage absolute agreement and
162 patterns of disagreement. The inter-rater reliability of EDACS levels assigned independently by pairs
163 of SaLTs at TP1 and across all time points was examined using the Intra-Class Correlation Coefficient
164 (ICC). The ICC (two-way random effects, single measure, absolute agreement) was calculated to
165 examine the level of agreement between raters. ICC values of 0.9 or higher are required for the use
166 of EDACS to be considered clinically reliable; ICC values of 0.7 or higher are acceptable for measures
167 in groups³³.

168 The stability of EDACS over time was examined by comparing children's EDACS levels recorded at
169 each of the TPs by SaLT1. The ICC was calculated to examine the level of overall agreement in EDACS
170 levels across all time points (two-way random effects, single measure, absolute agreement). ICC
171 values higher than 0.9 indicate high levels of agreement and stability of EDACS levels over time³³.
172 Five case studies were selected and summarised to illustrate study findings.

173 The association between eating and drinking ability and other functional abilities measured using
174 other Functional Classification Systems was examined using Kendall's tau b (τ)³⁴.

175 **Results**

176 A computer search of the clinical services caseload identified 97 eligible children with CP, from 373
177 case records. 276 records were of children who did not have CP or where there was insufficient data
178 to record EDACS levels over time. Information recorded from case notes is summarised in **Table 3**.

179 **Interrater Reliability:**

180 SaLT1 and SaLT2 used EDACS to independently rate the eating and drinking abilities of 50 children at
181 TP1: absolute agreement between SaLT1 and SaLT2 was 62% (ICC=0.8; 95%CI 0.67-0.89) indicating
182 acceptable agreement and reliability. See **Table 4**. SaLT1 and SaLT3 used EDACS to independently
183 rate the eating and drinking abilities of 24 children over 4 different TPs: absolute agreement
184 between SaLT1 and SaLT3 was 85% (ICC=0.95; 95% CI 0.92-0.98) indicating excellent agreement and
185 reliability³³. The use of EDACS by SaLT1 and SaLT3 is summarised in **Table 5**.

186 **Stability of EDACS Levels:**

187 The ICC examining the level of overall agreement in EDACS levels across all time points was 0.97
188 (95% CI 0.96-0.98). The high ICC of 0.97 indicates that EDACS levels remained stable over time, with
189 excellent agreement across time points³³.

190 The assigned EDACS level remained constant over time for 86% of children. The EDACS level assigned
191 changed by one level for 14 children. 3/14 showed improvements to eating and drinking abilities
192 from Level IV to Level III. 10/14 children had increased limitations to eating and drinking abilities

193 which occurred between 12 and 19yrs. Increasing limitation occurred at different EDACS levels: 6
194 children moved from Level IV to V; 4 children moved from Level III to IV and 1 child moved from
195 Level II to III. 10/11 children who lost function had orthopaedic issues and/or seizures (7 children
196 GMFCS V; 3 children GMFCS IV). See **Table 6** for summary of changes to function over time.

197 **Relationship between EDACS levels and other areas of function:**

198 There was a statistically significant moderate positive correlation between EDACS levels and all FCSs
199 (ranging from 0.53-0.75)³⁴: the highest associations were between someone's ability to use
200 intelligible speech and their eating and drinking ability and their ability to use their hands and eating
201 and drinking ability. See **Table 7** for associations between EDACS levels and other areas of function.

202 Children with the most limitations to eating and drinking were the most dependent upon enteral
203 nutrition: all 16 children classified as EDACS V received enteral nutrition/hydration; 26/36 children
204 classified as EDACS IV received some form of enteral nutrition; 6 children classified as EDACS I, II or
205 III received some form of enteral nutrition/hydration. Enteral nutrition was used to address safety
206 concerns linked to aspiration, hydration and nutritional concerns linked to inefficient suboptimal
207 intake and in some instances behavioural issues. The presence of a gastrostomy did not indicate
208 unsafe swallow.

209

210 **Case Studies:**

211 **Case Study 1:** Female (GMFCS I, MACS I, VSS III, CFCS III, EDACS IV at TP 1). EDACS level changed
212 from level IV to Level III between ages 3 and 6 years as she learnt skills to bite and chew soft lumps
213 of food, and drink thin fluids.

214 **Case Study 2:** Male (GMFCS V, MACS V, VSS IV, CFCS V, EDACS IV at TP1). EDACS level changed from
215 Level IV to V between 17 and 19 years. He experienced progressive scoliosis in adolescence and
216 other orthopaedic challenges. He also experienced a series of chest infections prompting a
217 videofluoroscopic investigation of swallowing (VFSS) which revealed aspiration of food and fluids
218 when eating and drinking. He needed to rely solely on enteral feeding for nutrition and hydration.

219 **Case Study 3:** Male (GMFCS IV, MACS IV, VSS IV, CFCS IV, EDACS III at TP1). EDACS level changed
220 from III to IV between 12 and 14 yrs. Silent aspiration was demonstrated on VFSS linked to strong
221 dystonic spasms affecting posture and respiratory control. The risk of aspiration during eating and
222 drinking was reduced by modification of food/fluid textures with increased opportunities to exercise
223 and change position throughout the day.

224 **Case Study 4:** Female (GMFCS III, MACS III, VSS III, CFCS III, EDACS III at TP1). EDACS III remained
225 stable from age 5yrs to 14yrs. Concerns about weight were linked to her limited inefficient intake of
226 food at age 5; at age 14 she managed larger volumes of food with no concerns about her weight
227 gain, although EDACS level remained the same.

228 **Case Study 5:** Male (GMFCS IV, MACS IV, VSS IV, CFCS III, EDACS IV at TP1). EDACS IV remained stable
229 over time with concern about lack of weight gain linked to limited oral intake; introduction of

230 gastrostomy age 16yrs led to a gradual loss of interest in eating/drinking although he was always
231 offered food and drink.

232 **Discussion:**

233 EDACS is a member of the family of functional classification systems for people with CP, which
234 includes the GMFCS, MACS and CFCS¹. The application of the GMFCS and MACS in retrospective²⁴
235 and prospective^{23,25,26} studies provides strong evidence for their discriminative and predictive
236 validity. The discriminative and predictive validity of EDACS requires further investigation. This study
237 is the first to investigate the stability of EDACS levels over time for a group of children and young
238 people with CP, providing some preliminary findings to inform future research. Demonstrating
239 stability of EDACS levels over time is the first step in the process of building the case for its use
240 prognostically. EDACS has potential to provide a map for health professionals working with children
241 with CP and their families to consider likely future outcomes, and limits to change.

242 The different levels of EDACS make clinical sense as a way to describe the eating and drinking
243 abilities of children and young people with CP in both clinical and research contexts. It has been
244 highly recommended as a research tool to describe the characteristics of a study population^{38,39}.
245 Important clinical information about children's usual eating and drinking performance at mealtimes
246 can be reliably captured and shared with other health professionals in order to improve treatment
247 and management, including the prevention of respiratory harm^{12,39}. It can form the basis of
248 conversations with parents about their children's abilities and a context within which to identify risks
249 associated with eating and drinking and options to manage these in different settings. However, the
250 full potential of EDACS to inform clinical practice is yet to be exploited.

251 This study demonstrates the reliability and stability of EDACS when applied retrospectively using
252 case records supporting its use in clinical and research contexts. Speech and language therapists
253 were able to consistently assign EDACS levels retrospectively from case records. The reliability of the
254 conversion of qualitative clinical data into ordinal scale data by different raters was tested at the
255 initial time point, and over all time points. This study supports the proposition that a child's eating
256 and drinking ability would remain at the same EDACS level overtime. If change in eating and drinking
257 ability occurs for some individuals at the margins between levels, this is likely to be by one level only.

258 The retrospective application of EDACS in this study reveals changes to eating and drinking abilities
259 that sometimes occur in adolescence. Experienced clinicians anecdotally report changes to eating
260 and drinking ability associated with ageing³⁷; the lack of a measurement tool suitable for use in
261 epidemiological studies has hampered the collection of such evidence. Each case study illustrates
262 the stability of eating and drinking ability defined by EDACS, including limits to change by one level,
263 where it occurs. Case 1 illustrates a change of EDACS level by one level with learning of new skills.
264 Cases 2 and 3 show increasing limitations to eating and drinking ability associated with adolescence,
265 orthopaedic and postural changes. Closer examination of cases where EDACS levels remain stable,
266 reveal changes to the extent to which someone makes use of underlying eating and drinking abilities
267 (Case 4 and Case 5).

268 The use of EDACS in combination with other FCSs communicates a helpful summary about a child's
269 function to others including the wider health care team. The moderate association between EDACS
270 and other FCSs is evidence of discriminative construct validity: it measures aspects of function which

271 are connected to but distinct from other aspects of function. The GMFCS is used as a measure of
272 severity of CP, and has been used to estimate life expectancy, and risks to health associated with
273 unsafe eating^{35,36}. However, the GMFCS does not discriminate between those children whose eating
274 and drinking is safe and efficient and those at risk of choking or of aspiration. The ability to use
275 speech (VSS) is most closely related to someone's eating and drinking ability (EDACS). However, the
276 relationship is not strong enough to use VSS to predict mealtime safety and efficiency. The
277 relationship between MACS and CFCS and EDACS levels also show only a moderate positive
278 correlation. Each of the FCSs used in this study measures distinct aspects of someone's day to day
279 function and none can be used as proxy measures of eating and drinking ability. Similarly the
280 presence of a feeding tube cannot be used as a proxy measure of unsafe swallow.

281 The study population demonstrated the full range of eating and drinking ability captured by EDACS
282 level I to V; in contrast, the sitting, standing and walking ability of the majority of children would be
283 classified as GMFCS III-V. The population represents children who experience the greatest
284 limitations to function as a result of CP. The clinical impetus to develop EDACS arose from the
285 acknowledged need to consider eating and drinking ability as a separate aspect of functioning¹⁹.

286 There are a number of limitations to this study because it is based on the retrospective examination
287 of case records of a clinical population accessing multi-professional healthcare in a community
288 setting.

289 The collection of retrospective data is limited by the quality of historical records. Some case records
290 contained limited information about eating and drinking abilities. The gaps between time points
291 were determined by availability of case record data rather than by pre-determined ages.
292 Consequently, there is variation between time points for each case. The earlier case records lacked
293 the consistent format of later records, reflected in the lower reliability value across Time Point 1
294 between SaLT 1 and 2. The case note materials could only be accessed by SaLTs who were members
295 of the clinical team. All three SaLTs had worked at the specialist centre for 10 or more years. They
296 each knew some of the children included in the study and were sometimes familiar with the details
297 of individual children's eating and drinking; this may have had an impact on how they assigned
298 EDACS levels from case records. All ratings by SaLTs were undertaken independently of one another.
299 SaLT2 assigned a level to each child only once and was blind to EDACS levels assigned by SaLT1 and
300 SaLT3. SaLT1 and SaLT3 assigned EDACS levels with knowledge of previous EDACS level they had
301 each assigned to that individual.

302 The strength of the study is that it provides new insights into the eating and drinking abilities of
303 children with CP over six or more years. It captures changes in eating and drinking ability associated
304 with adolescence.

305 Like the other FCSs, EDACS provides ordinal descriptions of function that is not suitable for use as an
306 outcome measure in the context of therapeutic intervention¹. All children within the study received
307 some input from therapists as part of ongoing health care and habilitation. Twenty-four hour
308 postural management programmes⁴⁰ and multi-professional patient centred healthcare typify the
309 interventions received by each child. Therapy was targeted to support safe and efficient mealtime
310 management and participation, and to optimise available movements associated with eating and
311 drinking. In some cases, therapy was specifically targeted to improve eating and drinking function.
312 This study does not identify the impact of therapeutic intervention on children's eating and drinking

313 abilities. Whilst an intervention would not be expected to change a classification level, at the outset
314 of this study it was not clear that EDACS would perform in the same way as the GMFCS and MACS
315 over time.

316 The next step in assessing the stability of EDACS would be a prospective cohort study charting the
317 eating and drinking ability of children with CP over time to evaluate the predictive validity of EDACS.

318

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326

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450 **Tables:**

451 **Table 1: Simplified summary descriptions of Functional Classification Systems suitable for use with**
452 **people with cerebral palsy.**

	Gross Motor Function Classification System	Manual Ability Classification System
Level I	Walks without limitations	Handles objects easily and successfully
Level II	Walks with limitations	Handles most objects but with somewhat reduced quality and/or speed of achievement
Level III	Walks using a handheld mobility device	Handles objects with difficulty; needs help to prepare and / or modify activities
Level IV	Self-mobility with limitations; may use powered mobility	Handles a limited selection of easily managed objects in adapted situations
Level V	Transported in a manual wheelchair	Does not handle objects and has severely limited ability to perform even simple actions
	Viking Speech Scale	Communication Function Classification System
Level I	Speech is not affected by motor disorder	Effective sender and receiver with unfamiliar and familiar partners
Level II	Speech is imprecise but usually understandable to unfamiliar listeners	Effective but slower paced sender and/or receiver with unfamiliar and familiar partners
Level III	Speech is unclear and not usually understandable to unfamiliar listeners out of context	Effective sender AND effective receiver with familiar partners
Level IV	No understandable speech	Inconsistent sender and / or receiver with familiar partners
Level V	-	Seldom effective sender and receiver with familiar partners

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454 **Table 2: Eating and Drinking Ability Classification System – summary descriptions of levels**

Level I	Eats and drinks safely and efficiently
Level II	Eats and drinks safely 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

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457 **Table 3: Summary of clinical information extracted from case notes including annual medical**
 458 **summaries, health reviews and therapy reports.**

Clinical Information		n=97 children (48 males)			
Age range		Time Point 1 2;10y – 17;02y mean 8;5y SD 3.98 Time Point 4 7;00y – 26;10y mean 17;02y SD 4.19			
Gastrostomy / enterally fed		48			
Orthopaedic issues		83			
Seizures		62			
Reflux		55			
CP Subtype (SCPE)		53 spastic bilateral (including mixed presentation) 33 dyskinetic 1 spastic unilateral 10 non-classifiable including 2 Worster Drought			
FCS levels TP1	GMFCS	MACS	CFCS	VSS	EDACS
Level I	3	5	5	8	9
Level II	1	12	3	7	13
Level III	10	13	28	23	23
Level IV	42	36	44	59	36
Level V	41	31	17	-	16

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460 **Table 4: Reliability measures associated with use of EDACS at time point 1 (TP1) by SaLT1 vs SaLT2,**
 461 **for 51% of randomly selected cases n=50**

		EDACS Levels SaLT2					Total
EDACS Levels SaLT1		I	II	III	IV	V	
	I	1	4	1	0	0	6
II	2	3	0	0	1*	6	
III	0	0	7	3	0	10	
IV	0	0	1	13	5	19	
V	0	0	0	2	7	9	
Total		3	7	9	18	13	50

462 *Disagreement of 3 levels between raters linked to difference of interpretation of case notes for
 463 child with a gastrostomy because of restricted food intake linked to behavioural issues: SaLT2
 464 understood presence of gastrostomy to indicate unsafe swallow.

465 **Table 5: Reliability measures associated with use of EDACS across all time points (TP1-TP4) for 25%**
 466 **of randomly selected cases by SaLT1 vs SaLT3**

		EDACS Levels SaLT3					Total
EDACS Levels		I	II	III	IV	V	
SaLT1	I	4	0	0	0	0	4
	II	5	11	0	0	0	16
	III	0	1	7	2	0	10
	IV	0	0	0	32	6	38
	V	0	0	0	0	28	28
Total		9	12	7	34	34	96

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469 **Table 6: Summary of changes to function over time by EDACS level for children with CP (n=97)**

Changes over time	Number n=97 (%)
No change of EDACS level	83 (86%)
Change by 1 EDACS level	14 (14%)
Change by 2 or more EDACS levels	0 (0%)
Improved abilities	3 (3%)
Improved abilities EDACS Level IV to III	3 (3%)
Loss of abilities	11 (11%)
Loss of abilities EDACS Level II to III	1 (1%)
Loss of abilities EDACS Level III to IV	4 (4%)
Loss of abilities EDACS Level IV to V	6 (6%)
Loss of abilities with orthopaedic issues or seizures	10 (10%) (3 GMFCS IV; 7 GMFCS V)
Loss of abilities between 12 – 19 years	10 (10%)
Loss of abilities between 3 – 5 years	1 (1%)

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472 **Table 7: Associations between children’s EDACS levels and levels of other Functional Classification**
 473 **Systems using Kendall’s tau b (τ)³⁴.**

Eating/drinking and speech: EDACS vs Viking Speech Scale	$\tau = 0.75$ $p < 0.001$
Eating/drinking and manual ability: EDACS vs MACS	$\tau = 0.66$ $p < 0.001$
Eating/drinking and gross motor function: EDACS vs GMFCS	$\tau = 0.58$ $p < 0.001$
Eating/drinking and communication: EDACS vs CFCS	$\tau = 0.53$ $p < 0.001$

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