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

*Diane Sellers[1]

Elizabeth Bryant[1,2]

Alison Hunter[1]

Vivienne Campbell[1]

Christopher Morris[3]

*Corresponding author: Diane Sellers, Chailey Clinical Services, Beggars Wood Road, North Chailey, East Sussex, BN8 4JN UK tel: +44 1825 722112 diane.sellers@nhs.net

[1]Chailey Clinical Services, Sussex Community NHS Foundation Trust, Brighton, East Sussex, UK

[2]University of Brighton, School of Health Sciences, Brighton, East Sussex, UK

[3]College of Medicine and Health, University of Exeter, Exeter, Devon, UK

Abstract:

Aim:

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

Method:

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

Results:

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

Interpretation:

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

Keywords:

Cerebral palsy, eating, drinking, EDACS, lifecourse

Background:

In the field of developmental disability it is well known that children and young people with the same condition, such as cerebral palsy (CP), vary considerably in their functional abilities. In recent years there has been a recognition of the utility of functional classification systems (FCS) which provide far more detail than a diagnostic label alone[1]. The oldest and most widely used of these FCS is the Gross Motor Function Classification System (GMFCS[2]); others have been developed to describe manual ability (Manual Ability Classification System MACS[3]), communication function (Communication Function Classification System CFCS[4]) and speech production (Viking Speech Scale VSS[5]). Each of these FCS describe function using distinct levels which are meaningful in daily life, replacing poorly defined, value laden terms such as mild, moderate and severe. The GMFCS, MACS and CFCS describe the full range of ability in 5 levels whereas the Viking Speech Scale uses 4 levels. See Table 1 for summary headings for each of the FCS.

FCS are considered to be useful in both clinical and research contexts because they can facilitate clear communication and planning at local and national level. Different FCS levels can be used to consider different clinical management options and enable clear reporting of research findings contributing to the clinical evidence base. In some cases FCS enable prediction of future outcomes through the stability of the assigned FCS level[1].

The contribution of eating and drinking difficulties to poor respiratory health has been well documented[6,7,8,9,]. Eating and drinking difficulties have also been associated with limited growth and poor health because of compromised nutritional intake[10,11] and in some instances can lead to premature death[12]. Prevalence figures for eating and drinking difficulties for children with CP vary widely depending upon definitions and measures used[13]. Prevalence rates include: 21% with "swallowing and chewing difficulties"[14]; 40% with "difficulties with eating"[15]; 55% with limitations to "chewing and swallowing"[16]; and 85% with "oro-pharyngeal dysphagia" assessed using two standardised measures[17]. A systematic review of ordinal scales used to measure eating and drinking ability of people with CP[18] identified 15 different scales: 13/15 were for clinician or researcher use only; 8/15 used the terms mild, moderate and severe with varying definitions to describe different aspects of eating and drinking impairment; none met recommended psychometric quality standards[41]. The review clearly identified the need for a new classification system of eating and drinking ability[18].

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

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

Each FCS provides broad categorical descriptions of function such that a level assigned to a child with CP is unlikely to change over time; if change does happen it is likely to be by just one level[1]. Ohrvall et al.[23] stated that it is necessary to consider the extent to which stability is influenced by potential changes in ability or whether it is due to inconsistency in use of the tool by different or the same raters. Research evaluating the GMFCS and MACS has demonstrated the stability of function over time in retrospective[24] and prospective studies[23,25,26].

There is limited evidence from longitudinal observations of the eating and drinking abilities of people with CP, hampered by the lack of consensus concerning measurement tools[27]. There is no clear understanding of the natural history of eating and drinking development in CP and no context within which to assess the impact of interventions to improve function. Currently, parents and health professionals make significant and emotive clinical decisions such as use of tube feeding without evidence of the stability of children and young people's eating and drinking ability. Conflict can arise between parents and health professionals when engaged in decision making linked to children's limitations in eating and drinking abilities[28,29,30]. Some parents resist proactive recommendations by the clinical team to use alternative and supplementary tube feeding for their child at a young age; this can result in limited growth and compromised health associated with chronic malnutrition for their child's lifetime[10]. The EDACS is a measurement tool that parents are able to understand, recognising their own child's eating and drinking abilities within the levels[19]. Discussions with parents could be enhanced with a clear statement about a child's eating and drinking ability using EDACS together with research evidence about how likely it is that this level will change in the future.

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

Method:

This study was carried out as a retrospective case note review, following a similar study design employed in retrospective examination of GMFCS levels from case notes by Wood and Rosenbaum[24]. The study took place at a centre providing specialist care to children and young people with complex neuro-disability, part of a community NHS trust in the UK. The multi-professional nutrition team manage the nutritional and hydrational intake of children with complex neuro-disability; team members include dietitian, neuro-developmental paediatrician, speech and language therapist and specialist children's nurse. Recommendations for safe and efficient mealtime support are provided for parents and care staff within a prescribed format in order to optimise nutrition and mealtime

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

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

Identification of Cases:

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

Data extraction and coding:

Case notes were used to record the following information: sex, CP type following Surveillance of Cerebral Palsy in Europe classification tree[31], GMFCS level at each TP, presence of feeding tube and age at which tube insertion was carried out, presence of seizures, gastro-oesophageal reflux and orthopaedic issues. Case notes include annual medical reports which routinely summarise diagnosis, present and past problems, medication, investigations and interventions. Annual therapy reports are produced for each child which include descriptions of gross motor and communication function, manual and eating and drinking ability. The following FCS were used to describe different aspects of children's function: Manual Ability Classification System[3], Communication Function Classification System[4] and Viking Speech Scale[5] at TP1. See **Table 1** for summary descriptions of levels for GMFCS[2], MACS[3], CFCS[4] and Viking Speech Scale[5].

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

Eating and Drinking Ability Classification System Levels:

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

EDACS was published in 2014 and not routinely included in case records at the specialist centre until 2015. Each of the 5 levels of EDACS systematically describes the safety and efficiency of someone's eating and drinking ability using similar content to that contained in case records. Retrospective use of EDACS involved the conversion of qualitative clinical data into ordinal scale data. Clinical reports, case notes and annual mealtime guidance sheets produced following NHS National Patient Safety Agency[32] recommendations contain information about safety of swallowing, chewing ability, risk of

aspiration or choking, recommended food textures and fluid consistencies, positioning, assistance required at mealtimes and required techniques for each child. The reliability of classifying function using EDACS using clinical data as source material was tested in two ways. The lead author and first SaLT1 (DS) assigned EDACS levels for all cases across all time points. The second SaLT2 assigned EDACS levels for 51% of randomly selected cases at TP1. The third SaLT3 assigned EDACS levels for 25% of randomly selected cases across each of the time points. Reliability testing followed guidance set out in international quality standards[41]. The reliability of the use of EDACS by pairs of SaLTs was examined using two way contingency tables to consider percentage absolute agreement and patterns of disagreement. The inter-rater reliability of EDACS levels assigned independently by pairs of SaLTs at TP1 and across all time points was examined using the Intra-Class Correlation Coefficient (ICC). The ICC (two-way random effects, single measure, absolute agreement) was calculated to examine the level of agreement between raters. ICC values of 0.9 or higher are required for the use of EDACS to be considered clinically reliable; ICC values of 0.7 or higher are acceptable for measures in groups[33].

The stability of EDACS over time was examined by comparing children's EDACS levels recorded at each of the TPs by SaLT1. The ICC was calculated to examine the level of overall agreement in EDACS levels across all time points (two-way random effects, single measure, absolute agreement). ICC values higher than 0.9 indicate high levels of agreement and stability of EDACS levels over time[33]. Five case studies were selected and summarised to illustrate study findings.

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

Results

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

Interrater Reliability:

SaLT1 and SaLT2 used EDACS to independently rate the eating and drinking abilities of 50 children at TP1: absolute agreement between SaLT1 and SaLT2 was 62% (ICC=0.8; 95%CI 0.67-0.89) indicating acceptable agreement and reliability. See **Table 4**. SaLT1 and SaLT3 used EDACS to independently rate the eating and drinking abilities of 24 children over 4 different TPs: absolute agreement between SaLT1 and SaLT3 was 85% (ICC=0.95; 95% CI 0.92-0.98) indicating excellent agreement and reliability[33]. The use of EDACS by SaLT1 and SaLT3 is summarised in **Table 5**.

Stability of EDACS Levels:

The ICC examining the level of overall agreement in EDACS levels across all time points was 0.97 (95% CI 0.96-0.98). The high ICC of 0.97 indicates that EDACS levels remained stable over time, with excellent agreement across time points[33].

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

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

Relationship between EDACS levels and other areas of function:

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

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

Case Studies:

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

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

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

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

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

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

Discussion:

EDACS is a member of the family of functional classification systems for people with CP, which includes the GMFCS, MACS and CFCS[1]. The application of the GMFCS and MACS in retrospective[24] and prospective[23,25,26] studies provides strong evidence for their discriminative and predictive validity. The discriminative and predictive validity of EDACS requires further investigation. This study is the first to investigate the stability of EDACS levels over time for a group of children and young people with CP, providing some preliminary findings to inform future research. Demonstrating stability of EDACS levels over time is the first step in the process of building the case for its use prognostically. EDACS has potential to provide a map for health professionals working with children with CP and their families to consider likely future outcomes, and limits to change.

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

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

The retrospective application of EDACS in this study reveals changes to eating and drinking abilities that sometimes occur in adolescence. Experienced clinicians anecdotally report changes to eating and drinking ability associated with ageing[37]; the lack of a measurement tool suitable for use in epidemiological studies has hampered the collection of such evidence. Each case study illustrates the stability of eating and drinking ability defined by EDACS, including limits to change by one level, where it occurs. Case 1 illustrates a change of EDACS level by one level with learning of new skills. Cases 2 and 3 show increasing limitations to eating and drinking ability associated with adolescence, orthopaedic and postural changes. Closer examination of cases where EDACS levels remain stable, reveal changes to the extent to which someone makes use of underlying eating and drinking abilities (Case 4 and Case 5).

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

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

The study population demonstrated the full range of eating and drinking ability captured by EDACS level I to V; in contrast, the sitting, standing and walking ability of the majority of children would be classified as GMFCS III-V. The population represents children who experience the greatest limitations to function as a result of CP. The clinical impetus to develop EDACS arose from the acknowledged need to consider eating and drinking ability as a separate aspect of functioning[19].

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

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

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

Like the other FCSs, EDACS provides ordinal descriptions of function that is not suitable for use as an outcome measure in the context of therapeutic intervention[1]. All children within the study received some input from therapists as part of ongoing health care and habilitation. Twenty-four hour postural management programmes[40] and multi-professional patient centred healthcare typify the interventions received by each child. Therapy was targeted to support safe and efficient mealtime management and participation, and to optimise available movements associated with eating and drinking. In some cases, therapy was specifically targeted to improve eating and drinking function. This study does not identify the impact of therapeutic intervention on children's eating and drinking

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

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

Acknowledgements and Ethics:

Funding for the study was awarded by British Academy of Childhood Disability and Royal College of Paediatrics and Child Health Polani Prize, March 2015. Ethical approval for the research was conferred by NHS Health Research Authority REC reference 16/LO/0344.

Diane Sellers has received a research grant and honorarium funding from Nutricia Advanced Medical Nutrition UK 2017-2019.

All other authors have no conflict of interest to report.

References:

1 Rosenbaum P, Eliasson A, Hidecker MJC and Palisano R. Classification in Childhood Disability: Focusing on Function in the 21st Century. Journal Child Neurology, August 2014; vol. 29, 8: pp. 1036-1045.

2 Palisano R, Rosenbaum P, Walter S, Russell D, Wood E and Galuppi B (1997). Development and Reliability of a System to Classify Gross Motor Function of Children with Cerebral Palsy. Developmental Medicine and Child Neurology 39 p214 -223.

3 Eliasson AC, Krumlinde-Sunholm L, Rosblad B, Beckung E, Arner M, Ohrvall AM, Rosebaum P (2006). The Manual Ability Classification System (MACS) for Children with Cerebral Palsy: Scale Development and Evidence of Validity and Reliability. Developmental Medicine and Child Neurology 48 549-554.

4 Hidecker MJC, Paneth N, Rosenbaum P, Kent R, Lillie J, Eulenberg JB, Chester Ken JR, Johnson B, Michalsen L, Evatt M and Taylor K (2011). Developing and validating the Communication Function Classification System for individuals with cerebral palsy. Developmental Medicine and Child Neurology 53(8) 704-710.

5. Pennington L, Virella D, Mjøen T, da Graça Andrada M, Murray J, Colver A, Himmelmann K, Rackauskaite G, Greitane A, Prasauskiene A and Andersen G 2013. Development of The Viking Speech Scale to classify the speech of children with cerebral palsy. Research in developmental disabilities, 34(10), pp.3202-3210.

6. Taniguchi MH and Moyer RS (1994). Assessment of risk factors for pneumonia in dysphagic children: significance of videofluoroscopic swallowing evaluation. Developmental Medicine and Child Neurology, 36(6) 495–502.

7. Rogers B, Arvedson J, Buck G, Smart P and Msall M (1994). Characteristics of Dysphagia in Children with Cerebral Palsy. Dysphagia 9; 69-73.

8. Morton R, Wheatley R, and Minford J (1999). Respiratory tract infections due to direct and reflux aspiration in children with severe neuro-disability. Developmental Medicine and Child Neurology, 41(5) 329–334.

9. Cass H, Wallis C, Ryan M, Reilly S, and McHugh K (2005). Assessing pulmonary consequences of dysphagia in children with neurological disabilities: when to intervene? Developmental Medicine and Child Neurology, 47(5), 347–352.

10. Fung E, Samson-Fang L, Stallings V, Conaway M, Liptak G, Henderson R, Worley G, O'Donnell M, Calvert R, Rosenbaum P, Chumlea W and Stevenson R (2002). Feeding Dysfunction is associated with poor growth and health status in children with cerebral palsy. Journal of the American Dietetic Association 102 (3) 361-373.

11. Sullivan PB, Juszczak E, Lambert BR, Rose M, Ford-Adams ME and Johnson A (2002). Impact of feeding problems on nutritional intake and growth: Oxford Feeding Study II. Developmental Medicine and Child Neurology, 44(7) 461–467.

12. Glover G and Ayub M (2010). How people with learning disabilities die. Published by Improving Health and Lives: Learning Disabilities Observatory. http://www.improvinghealthandlives.org.uk/uploads/doc/vid_9033_IHAL2010-06%20Mortality.pdf accessed 21 September 2013.

13. Sellers, D. (2016), The impact of orofacial dysfunction in cerebral palsy. Developmental Medicine and Child Neurology, 58: 327-327. doi:10.1111/dmcn.12897

14. Parkes J, Hill N, Platt MJ and Donnelly C (2010). Oromotor dysfunction and communication impairments in children with cerebral palsy: a register study. Developmental Medicine and Child Neurology, 52: 1113-1119. doi:10.1111/j.1469-8749.2010.03765.x

15. Reid SM, McCutcheon J, Reddihough D and Johnson H (2012). Prevalence and predictors of drooling in 7- to 14-year-old children with cerebral palsy: a population study. Developmental Medicine and Child Neurology, 54: 1032-1036. doi:10.1111/j.1469-8749.2012.04382.x

16. Edvinsson, S. E. and Lundqvist, L. (2016), Prevalence of orofacial dysfunction in cerebral palsy and its association with gross motor function and manual ability. Developmental Medicine and Child Neurology, 58: 385-394. doi:10.1111/dmcn.12867

17. Benfer KA, Weir KA, Bell KL, Ware RS, Davies PS,Boyd RN (2013). Oropharyngeal dysphagia and gross motor skills in children with cerebral palsy. Pediatrics **131**: e1553–62

18. Sellers D, Pennington L, Mandy A and Morris C (2014a). A systematic review of ordinal scales used to classify the eating and drinking abilities of individuals with cerebral palsy. Developmental Medicine and Child Neurology 56: 313–322. doi:10.1111/dmcn.12313

19. Sellers D, Mandy A, Pennington L, Hankins M and Morris C (2014b). Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. Developmental Medicine and Child Neurology 56: 245–251. doi:10.1111/dmcn.12352

20. Benfer K, Weir K, Bell K, Ware R, Davies P and Boyd R (2017). The Eating and Drinking Ability Classification System in a population-based sample of preschool children with cerebral palsy. Developmental Medicine and Child Neurology, 59: 647-654. doi:10.1111/dmcn.13403

21. Van Hulst K, Snik D, Jongerius P, Sellers D, Erasmus C, and Geurts A (2018). Reliability, construct validity and usability of the Eating and Drinking Ability Classification System (EDACS) among Dutch children with Cerebral Palsy. Journal of pediatric rehabilitation medicine 11(2):115-124 DOI: 10.3233/PRM-170515

22. Tschirren L, Bauer S, Hanser C, Marsico P, Sellers D and Hedel H. (2018). The Eating and Drinking Ability Classification System: concurrent validity and reliability in children with cerebral palsy. Developmental Medicine and Child Neurology 60: 611-617. doi:10.1111/dmcn.13751

23. Öhrvall, A.-M., Krumlinde-Sundholm, L. and Eliasson, A.-C. (2014). The stability of the Manual Ability Classification System over time. Developmental Medicine and Child Neurology, 56: 185–189. doi: 10.1111/dmcn.12348

24. Wood, E. and Rosenbaum, P. (2000). The Gross Motor Function Classification System for Cerebral Palsy: a study of reliability and stability over time. Developmental Medicine and Child Neurology, 42: 292–296. doi: 10.1111/j.1469-8749.2000.tb00093.x

25. Rosenbaum PL, Walter SD, Hanna SE, Palisano RJ, Russell DJ, Raina P, Wood E, Bartlett DJ, Galuppi BE (2002). Prognosis for gross motor function in cerebral palsy: creation of motor development curves. Journal of the American Medical Association 288:1357–1363.

26. Palisano RJ, Cameron D, Rosenbaum PL, Walter SD and Russell D (2006). Stability of the Gross Motor Function Classification System. Developmental Medicine and Child Neurology, 48: 424–428. doi: 10.1111/j.1469-8749.2006.tb01290.x

27. Hidecker MJ, Hanna C, Rosenbaum P, Kent RD, Paneth N (2009). Cerebral Palsy Surveillance of Communication and Eating. Presented at the International Cerebral Palsy Conference Sydney Australia 2009 https://www.msu.edu/~hidecke1/Hidecker_et_al_Surveillance_Presentation.pdf

28. Mahant S, Jovcevska V and Cohen E (2011). Decision-making around gastrostomy-feeding in children with neurologic disabilities. Pediatrics, May 2011 pp.peds-2010.

29. Craig GM and Higgs P (2012). Risk owners and risk managers: Dealing with the complexity of feeding children with neurodevelopmental disability: Negotiating and communicating health risk. Health, Risk and Society, 14(7-8), pp.627-637.

30. Cowpe E, Hanson B and Smith CH (2014). What do parents of children with dysphagia think about their MDT? A qualitative study. BMJ open, 4(10), p.e005934.

31. Cans C (2007). Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Developmental Medicine and Child Neurology, 42(12), 816–824

32. NHS National Patient Safety Agency Mealtime Guidance
http://www.nrls.npsa.nhs.uk/resources/?entryid45=59823

33. Fitzpatrick R, Davey C, Buxton M and Jones D (1998). Evaluating patient-based outcome measures for use in clinical trials. Health Technology Assessment 2(14).

34. Kendall M (1938). A new measure of rank correlation. Biometrika **30** (1-2):81-89.

35. Sewell MD, Eastwood DM and Wimalasundera N (2014). Managing common symptoms of cerebral palsy in children. BMJ 349(7976), p.5474 doi: 10.1136/bmj.g5474

36. Strauss D, Brooks J, Rosenbloom L and Shavelle R (2008). Life expectancy in cerebral palsy: an update. Developmental Medicine and Child Neurology 2008;50:487-93.

37. Haak P, Lenski M, Hidecker MJC, Li M, Paneth N (2009). Cerebral palsy and aging. Developmental medicine and child neurology 51:16-23. doi:10.1111/j.1469-8749.2009.03428.x.

38. Schiariti, V. , Fowler, E. , Brandenburg, J. E., Levey, E. , Mcintyre, S. , Sukal-Moulton, T. , Ramey, S. L., Rose, J. , Sienko, S. , Stashinko, E. , Vogtle, L. , Feldman, R. S. and Koenig, J. I. (2018). A common data language for clinical research studies: the National Institute of Neurological Disorders and Stroke and American Academy for Cerebral Palsy and Developmental Medicine Cerebral Palsy Common Data Elements Version 1.0 recommendations. Developmental medicine and child neurology. doi:10.1111/dmcn.13723

39. Himmelmann K. Putting prevention into practice for the benefit of children and young people with cerebral palsy Archives of Disease in Childhood Published Online First: 18 July 2018. doi: 10.1136/archdischild-2018-315134

40. Gericke, T. (2006). Postural management for children with cerebral palsy: Consensus statement. Developmental Medicine and Child Neurology, 48(4), 244-244. doi:10.1017/S0012162206000685

41. Terwee CB, Bot SDM, De Boer MR, Van der Windt D, Knol DL, Dekker J, Bouter LM and de Vet HCW. (2007). Quality criteria were proposed for measurement properties of health status questionnaires. Journal of Clinical Epidemiology, 60(1), 34–42.

449

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

453

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

455

456

Table 3: Summary of clinical information extracted from case notes including annual medical 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

Table 4: Reliability measures associated with use of EDACS at time point 1 (TP1) by SaLT1 vs SaLT2, 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

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

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

	EDACS Levels SaLT3						**Total**
EDACS		**I**	**II**	**III**	**IV**	**V**	
Levels	**I**	4	0	0	0	0	4
SaLT1	**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

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%)

Table 7: Associations between children's EDACS levels and levels of other Functional Classification 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	$\tau = 0.53$ $p<0.001$