Mini-EDACS:

development of the Eating and Drinking Ability Classification System for young children with cerebral palsy

Cerebral palsy affects children and young people's lives in many different ways. Classification systems have been created to describe how cerebral palsy affects the ability to move (GMFCS)[1], to handle objects (MACS)[2], and to communicate with others (CFCS).[3] Each system classifies the full range of ability for each function using five levels, where Level I indicates few limitations, and Level V indicates most limitations to function.

Each classification system is easy to understand, and provides a common language for use across clinical practice and research.

Taking inspiration from these systems, we created the Eating and Drinking Ability Classification System (EDACS).[4] Cerebral palsy can limit the oral skills required for eating, drinking and swallowing, with risks of respiratory problems linked to direct aspiration of food and fluid into the lungs[5], and inadequate nutrition and hydration.[6, 7] EDACS describes five distinct levels of ability using the key features of safety and efficiency, from 3 years of age. See Figure 1.

We set out to extend EDACS to include descriptions of very young children with cerebral palsy (18 to 36 months), whose eating and drinking skills are still developing.

What did we do?

We developed Mini-EDACS in several stages.

Using existing evidence
We worked with researchers from Australia who had already collected mealtime video data of young children with cerebral palsy.[8] They applied EDACS to 130 video recordings of young children with cerebral palsy aged between 18 to 36 months. They identified where changes were needed to show the developing eating and drinking skills of younger children. We created an initial version of Mini-EDACS using the feedback from the team in Australia.

Consulting people with expert knowledge
We used a Delphi Survey to share Mini-EDACS with an international group of 89 people with expert knowledge. The Delphi Survey is a method used to seek consensus or agreement among a large group of people who do not necessarily meet each other face to face.

> "Most people found Mini-EDACS easy to us."

We collected their suggestions, and refined the Mini-EDACS, and shared it again in another round of the Delphi survey. Most participants agreed with descriptions of young children's eating and drinking abilities in the first round (more than 90%). We made some slight changes to Mini-EDACS from recommendations by participants.

Checking the reliability of Mini-EDACS
The final version of Mini-EDACS was used by pairs of speech and language therapists to classify the eating and drinking abilities of 43 young children with cerebral palsy from video recordings of usual mealtimes. Parents and carers also provided some extra information about their child's usual mealtimes. Speech and Language Therapists were chosen because they typically assess and manage the eating and drinking difficulties linked to cerebral palsy. We examined whether speech and language therapists agreed with one another about levels of ability. Finally, we asked parents and therapists what they thought about using Mini-EDACS.

What did we find?

Experts agreed that Mini-EDACS describes the eating and drinking abilities of children from the age of 18 months to 36 months in five levels; the amount of assistance someone requires to bring food and drink to the mouth is described in three levels. Key features include:

- **safety** of eating and drinking linked to the risk of choking or aspiration (entry of particles of food and fluid into the lungs)
- **efficiency** of eating and drinking linked to time taken and how much food or fluid is lost from the mouth
- each Mini-EDACS level **describes young children's developing biting, chewing and swallowing abilities**, food and fluid textures that are managed and breath changes associated with eating and drinking

We found that speech and language therapists used Mini-EDACS in similar ways to each other to describe the eating and drinking abilities of the same children. They agreed with one another 58% of the time, kappa=0.43, indicating moderate agreement.[9] Measures of consistency of use of Mini-EDACS by speech and language therapists were acceptable: Intraclass Correlation Coefficient: 0.78 (95% CI 0.63-0.87).[10]

Parents and speech and language therapists thought Mini-EDACS was a useful tool. One parent commented that Mini-EDACS was clear because each level spells out the requirements, so it was easy to identify the right level for their child. Another parent said that no-one had ever said that a rating score even existed for children with cerebral palsy and that overall they found using Mini-EDACS to be a positive experience. Most people found it easy to use.

WHERE TO FIND OUT MORE?

EDACS plus **MINI-EDACS** is free to download from **www.edacs.org**. The study findings are published in Developmental Medicine and Child Neurology.[11]

What could be done next?

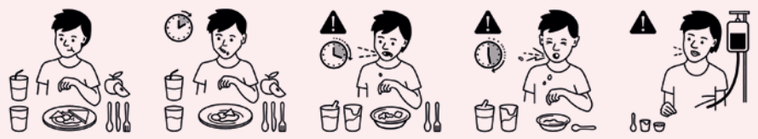
The new Mini-EDACS is now part of the Eating and Drinking Ability Classification System which has been endorsed by experts in cerebral palsy, eating and drinking, and research, and also by people with cerebral palsy and parent carers. EDACS is a reliable way of classifying someone's eating and drinking abilities for use in both clinical and research contexts. The reliability of Mini-EDACS requires further study. Mini-EDACS classifications made in person with better knowledge of a young child's eating and drinking may lead to higher reliability than we found using videos.

Project Team

- **Dr Diane Sellers**, Speech and Language Therapist and Research Fellow, Sussex, UK
- **Christopher Morris**, Professor of Child Health Research, Exeter, UK
- **Lindsay Pennington**, Speech and Language Therapist and Reader, Newcastle, UK
- **Elizabeth Bryant**, Senior Research Fellow, Brighton, UK
- **Kath Benfer** Post-doctoral researcher, Queensland, Australia
- **Kelly Weir**, Speech pathologist and Allied Health Research Fellow, Southport, Australia

This independent research was funded by Nutricia, to include Diane Sellers' and Elizabeth Bryant's time, administration and costs for study participants. Other researchers offered their time pro bono. The views expressed are those of the author only.

Eating and Drinking Ability Classification System from 3 years: descriptors and illustrations[12]



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 VI
Eats and drinks with significant limitations to safety.

Level V
Unable to eat or drink safely – tube feeding may be considered to provide nutrition.

Figure 1. Eating and Drinking Ability Classification System: descriptors and illustrations

DR DIANE SELLERS
Clinical Academic Speech and Language Therapist, Sussex, UK

References:

1. Costello CL, et al. Growth Restriction in Infants and Young Children with Congenital Heart Disease. Congenit Heart Dis. 2015;10(5):447-56.
2. Palisano R, et al. Content validity of the expanded and revised Gross Motor Function Classification System. Developmental Medicine & Child Neurology. 2008; 50(10):744-50.
3. Eliasson A,-C, et al. The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. Developmental Medicine & Child Neurology. 2006; 48:549-554.
4. Hidecker M, et al. Developing and validating the Communication Function Classification System for individuals with cerebral palsy. Developmental Medicine & Child Neurology. 2011; 53(8):704-10.
5. Sellers D, et al. Development and reliability of a system to classify the eating and drinking ability of people with cerebral palsy. Developmental Medicine & Child Neurology. 2014; 56 (3):245-51.
6. Gibson N, et al. Prevention and management of respiratory disease in young people with cerebral palsy: a consensus statement. Developmental Medicine and Child Neurology. 2021; 63:172-182.
7. Fung E, et al. Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy. Journal of the American Dietetic Association. 2002; 102(3):361-73.
8. Sullivan P, et al. Impact of feeding problems on nutritional intake and growth: Oxford Feeding Study II. Developmental Medicine & Child Neurology. 2002; 44(7):461-7.
9. Benfer KA, et al. Oro-pharyngeal dysphagia in preschool children with cerebral palsy: oral phase impairments. Research in Developmental Disabilities. 2014; 35(12):3469-3481.
10. Cohen JA. A coefficient of agreement for nominal scales. Educational and Psychological Measurement. 1960; 20:37-46.
11. Fitzpatrick R, et al. Evaluating patient-based outcome measures for use in clinical trials. Health Technology Assessment. 1998; 2(14).
12. Sellers D, et al. Mini-EDACS: development of the Eating and Drinking Ability Classification System for young children with cerebral palsy. Developmental Medicine and Child Neurology. 2022;0:1-10.

Small Talk | Autumn 2022