The Eating and Drinking Ability Classification System (EDACS) for people with cerebral palsy: a common language to aid understanding.

Key findings

- The new Eating and Drinking Ability Classification System (EDACS) is a reliable way to describe how people with cerebral palsy usually eat and drink.
- EDACS describes the full range of eating and drinking ability in five distinct levels for people with cerebral palsy from the age of three years, including assistance required at mealtimes.
- Parents of children with cerebral palsy, adults with cerebral palsy, various types of health professionals and researchers helped to develop the EDACS.
- Families and professionals can use the EDACS to share knowledge, and to work in partnership to improve care.

Who did the study and why?

This study was led by researchers at Chailey Heritage Clinical Services, part of Sussex Community NHS Trust. We worked together with a team of people in the UK including a parent of a child with cerebral palsy (CP), and researchers from the PenCRU at the University of Exeter, Newcastle University, University of Brighton and University of Southampton.

The idea for the study came from clinicians at Chailey Heritage Clinical Services in their work with children with CP and their families.

Sometimes impairments linked to cerebral palsy can limit the skills that someone needs to eat, drink and swallow safely and efficiently.

This can cause serious problems if particles of food or fluids enter the lungs, or if the person has inadequate nutrition or dehydration.

We found no systematic way existed to describe how eating and drinking ability was affected in people with CP.

Background

Cerebral palsy affects people's lives in many different ways. Classification systems have been created to describe how cerebral palsy affects their ability to move (sit, stand and walk), to handle objects, and to communicate with others. Each of these systems classifies the full range of ability for each function using five levels, where Level I indicates least limitations, and Level V indicates the most limitations to function.

Each of the classification systems provides a common language that is easy to understand which can be used in clinical practice and research.

We took inspiration from these systems and set out to create a new Eating and Drinking Ability Classification System for people with cerebral palsy – known as EDACS.

What did we do?

We developed the new Eating and Drinking Ability Classification System in several stages.

Searching the evidence

We searched online libraries for all the different ways that eating and drinking by people with CP has been classified and measured. We found 15 different scales, but none met recommended standards for robust measurement.

Therefore, there was a need to develop a system to classify eating and drinking ability for people with CP that met the standards.

Creating a draft classification system

We created an initial version of EDACS using our clinical experience and from what we read about eating and drinking in research journals and text books.

Consulting people with expert knowledge

We arranged meetings around England to share our ideas and to hear the ideas of people who have expert knowledge about cerebral palsy and eating and drinking.

We consulted parent carers, people with cerebral palsy, experienced health professionals and researchers. After each meeting we made changes to EDACS and shared the revised version with the next group. We repeated this seven times until no more new ideas were collected.

We organised the meetings to encourage everyone to have their say. No more than 10 people took part in each group and 54 people took part altogether.

We then shared the EDACS with a large international group of 95 people with expert knowledge using a Delphi Survey. The Delphi Survey is a method used to find consensus or agreement among a large group of people who do not meet each another face to face.

We collected their suggestions, and refined the EDACS, and shared it again with the Delphi survey participants until 80% or more agreed with it.

Checking the reliability of EDACS

The descriptions of eating and drinking ability in the final version of EDACS were used by pairs of speech and language therapists to classify the eating and drinking abilities of 100 children with cerebral palsy they knew well. 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.

We also compared the way that parents and speech and language therapists used EDACS to classify 48 children's eating and drinking ability.

Finally, we asked parents and therapists what they thought about using EDACS.

What did we find?

EDACS describes the eating and drinking abilities of children from the age of three years to adulthood in five levels. The amount of assistance someone requires to bring food and drink to the mouth is described in three levels.

EDACS identifies safety as a key feature of eating and drinking linked to the risk of choking or aspiration (entry of particles of food and fluid into the lungs).

Another key feature is how efficiently someone eats and drinks linked to the time taken and how much food or fluid is lost from the mouth.

Each of the five levels of EDACS includes descriptions about biting, chewing and swallowing, food and fluid textures that are managed and breath changes associated with eating and drinking.

We found that speech and language therapists used EDACS in similar ways to each other to describe the eating and drinking abilities of the same children. They agreed with one another 78% of the time.

Parents and speech and language therapists agreed with one another 58% of the time. When parents disagreed with speech and language therapists they consistently chose a level of ability that was one higher than the one chosen by the speech and language therapist, describing greater levels of ability.

Some of the people we talked to thought that the differences might be linked to children feeling more comfortable at home with people who knew them well; others thought that sometimes speech and language therapists can be more cautious than parents in order to keep children safe in a school environment.

Many people thought that EDACS was an excellent tool. Some people said it would be a useful common language to foster communication and partnership between parents, health and care professionals. Others said EDACS could also be used in research and education settings.

Who reviewed our research to make sure it was done well?

The study is published in a journal called Developmental Medicine and Child Neurology. The journal will only publish research after independent experts have decided that the study was done well and that it was important enough to publish.

What could be done next?

The new Eating and Drinking Ability Classification System has been endorsed by experts in cerebral palsy, eating and drinking, and research, and also by people with CP and parent carers. EDACS is a reliable way of classifying someone's eating and drinking abilities for use in both clinical and research contexts.

In future studies we would like to find out about how people use EDACS is in a range of settings. We would also like to carry out more comparisons to check the reliability between the ways that parents and health professionals use EDACS.

A number of research teams from around the world have approached us to translate EDACS into different languages. Several research teams have requested permission to include EDACS as a measure in their studies.

Many of the participants wanted EDACS to describe children's eating and drinking ability from diagnosis of cerebral palsy to adulthood. We do not currently have enough information to do this for children younger than three years.

The Eating and Drinking Ability Classification System is freely available to all to download from the following web address **www.EDACS.org** .

The full version of this study is published in the journal Developmental Medicine and Child Neurology. If you would like a copy please contact Diane Sellers at diane.sellers@nhs.net .

The team that carried out the research are:

- Diane Sellers, Speech and Language Therapist and Research Fellow at Chailey Heritage Clinical Services, part of Sussex Community NHS Trust
- Chris Morris, Senior Research Fellow at PenCRU, University of Exeter Medical School
- Lindsay Pennington, Speech and Language Therapist and Principal Research Fellow at Newcastle University
- Anne Mandy, Reader at the University of Brighton
- Matthew Hankins, Clinical Psychologist and Statistician at the University of Southampton
- Mike Carter, Parent of child with cerebral palsy
- Terry Pountney, Physiotherapist and Senior Research Fellow at Chailey Heritage Clinical Services
- Sarah Ford, Research Administrator at Chailey Heritage Clinical Services

We are grateful to PenCRU for permission to use the template for the plain language summary.