NIHR Applied Research Collaboration Kent, Surrey and Sussex

Implementing the Eating and Drinking Ability Classification System (EDACS) across health and social care settings for adults with cerebral palsy (CP)

Diane Sellers, Sussex Community NHS Foundation Trust



EATING AND DRINKING ABILITY CLASSIFICATION SYSTEM

Key Findings:

• Eating and Drinking Ability Classification System (EDACS) is a reliable way to describe how people with cerebral palsy (CP) usually eat and drink, including both adults and children.

• Families and professionals can use EDACS to share knowledge, and to work in partnership to improve care.

• Specialist health and social care for adults with CP is limited, making it challenging to implement EDACS across the life-course for those with this lifelong condition.

People with cerebral palsy (CP) told us about their experiences linked to eating, drinking and swallowing. Specialist healthcare finishes when people leave children's services. Only adults with CP who have a learning disability are eligible for support from specialist health professionals, working in learning disability services. People with CP described their frustrations and difficulties in getting help from mainstream healthcare services, where there is a lack of understanding and knowledge about the lifelong consequences of CP. People told us about disagreements concerning perceptions and management of risks associated with eating, drinking and swallowing. People with CP and their families also told us about the lack of their involvement in healthcare decisions, with subsequent fears about approaching healthcare professionals and their choices to manage alone.

Participants thought that EDACS provided a language to talk about someone's lived experience of eating, drinking and swallowing. People with CP, family members and those working in social care thought that EDACS could help share meaning in conversations with health professionals.

Participants thought EDACS was useful in transition-planning and ensuring continuity of information across health and social care settings. They also thought that EDACS made it possible to track changes to someone's eating and drinking over time, enabling appropriate and timely referrals to support changing skills.

We found that EDACS was broadly reliable when used by speech and language therapists and those working closely with adults with CP. Adults with CP and people who provide care support used EDACS in similar ways.

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Public and Community Involvement:

We carried out the research with advice and support of a group of adults with CP, and their families. We have been advised by some of the leading charities who represent the needs and interests of those with CP in the UK.

People with CP and their families are contributing to the production of the animation of study findings.

Dissemination:

We are developing an animation to share our research findings with people with CP, their families and carers, as well as health and social care professionals.

Eating and Drinking Ability Classification System for adults with CP is freely available to all to download from the following web address <u>www.edacs.org</u>.

Impact and Implementation:

Eating and Drinking Ability Classification System has been endorsed by adults with CP, their families and those who provide care support as well as health and social care professionals.

Publications:

We are presenting our findings at the European Academy of Childhood Disability in Bruges in May 2024.

We are preparing two papers for publication in scientific journals:

Systematic review: How do healthcare professionals, adults with cerebral palsy, families and caregivers discuss eating, drinking and swallowing difficulties and risks to health?

Implementing the Eating and Drinking Ability Classification System (EDACS) across health and social care settings for adults with cerebral palsy to improve shared decision-making and eating and drinking outcomes

What next?

Different health and social care organisations can implement the use of EDACS to better meet the eating and drinking needs of those with CP and thereby reduce significant risks to health and improve quality of life.

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