

# Practical applications of the eating and drinking ability classification system (EDACS)

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*Excellent care at the heart of the community*

# EDACS

- Eating and Drinking Ability Classification System
- Sellers et al. 2014 DevMedChildNeuro
- [www.edacs.org](http://www.edacs.org)

# Overview

- Content
- Utility
- Clinical questions
- Prognosis?



# Cerebral Palsy

Affects many areas of function including:


- Sitting, standing, walking
- Speech and language development
- Use of hands
- Senses including vision and hearing
- *Eating, drinking and swallowing*

# Cerebral Palsy – cause of death (UK)

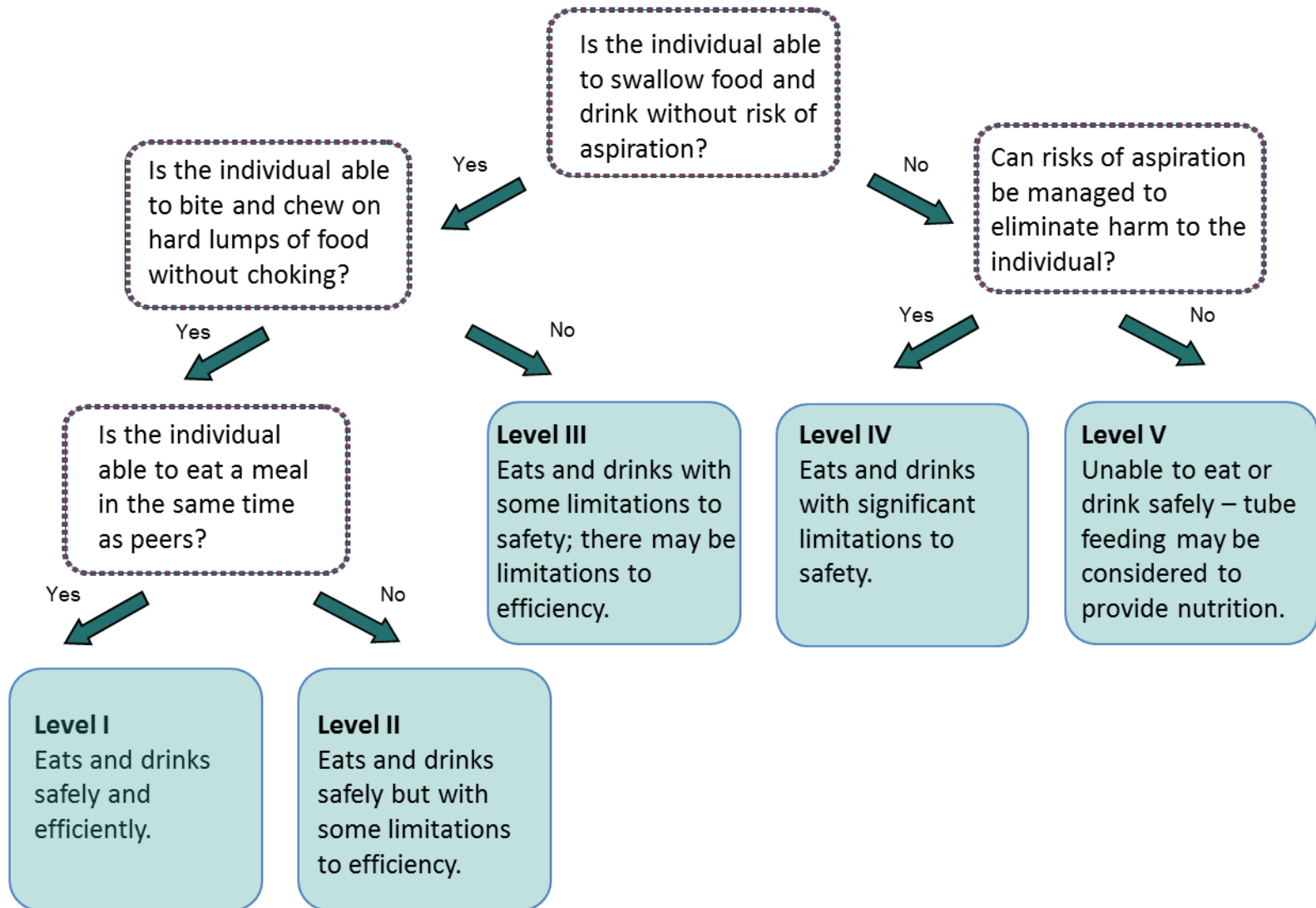
- 22% of identified deaths for people with CP resulted from solids or liquids in their lungs or windpipe
- Where difficulty swallowing was mentioned on death certificate (only 3%) cause of death in 60% of these cases was solids or liquids in the lungs or windpipe

Improving Health and Lives Learning Disabilities Observatory (2010)


# EDACS – Key Features

- Safety - aspiration and choking
  - Efficiency - food loss and time taken
  - 5 level ordinal scale - describing full range of eating and drinking ability of people with CP
  - 3 level ordinal scale – describing assistance required in bringing food and drink to mouth
  - Age Range - from 3 years to adulthood
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# Eating and Drinking Ability Classification System



# Levels of Assistance Required

- **Independent (Ind)** indicates that individuals are able to bring food and drink to their own mouth without any assistance.
  - **Requires Assistance (RA)** indicates that an individual needs help to bring food or drink to the mouth, either from another person or through the use of adapted equipment.
  - **Totally Dependent (TD)** indicates that an individual is totally dependent upon another to bring food or drink to the mouth.
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# Distinctions between levels


## Distinctions between levels II and III

Individuals in Level II manage most age appropriate food textures and drink with some slight modifications. Individuals at Level III will need more food textures to be modified in order to reduce risk of choking.

# EDACS

- Standardises severity ratings of eating and drinking ability
- Replaces terms such as “mild”, “moderate” and “severe impairment” which lack consistent definition
- Use of such terms dependent upon experience
- Established reliable systematic way of rating eating and drinking ability

# Danielle – description of function

- **GMFCS IV:** Self mobility with limitations; may use powered mobility
  - **MACS III:** Handles objects with difficulty; needs help to prepare and / or modify activities
  - **Viking III:** Speech is unclear and not usually understandable to unfamiliar listeners out of context
  - **CFCS IV:** Inconsistent Sender and / or Receiver with familiar partners
  - **EDACS II Requires Assistance:** Eats and drinks safely but with some limitations to efficiency
- 



# Clinical Utility

- What is it good for?
- Why should we add another tool to the toolkit?

# Means of communication



# EDACS

- Improves communication between professionals
- Enables planning
- Identifies risks linked to eating and drinking

# Communication with parents




# Consistent shared language

- Provides parents with context to understand own child's abilities in relation to others with CP
- Obtain parents' views about their child's eating + drinking ability in consistent way
- Conversations about risk, gastrostomy, food and fluid textures etc.
- Adjusts power dynamic and allows for parents to share their knowledge in meaningful way


# Examples of application

## Children EDACS V

- Good oral care routines
  - Tastes or flavours programme
  - Caution when teeth cleaning - foam free toothpaste and suction
  - Reduce aspiration risk when swimming etc
  - Maximise participation in mealtimes – tastes, flavours, smells etc.
  - Postural management to reduce posterior aspiration of saliva especially in lying
- 


# Examples of application

## Children EDACS IV + III


- Food/fluid textures and mealtime techniques
  - Posture
  - Breathing and chest health
  - Nutritional and hydrational status and growth parameters
  - Timing of swallowing
  - Choking risks
  - Maximise enjoyment, choices, participation
  - Best formulation of oral medication?
- 

# Examples of application

## Children EDACS II + I

- Time allowed for meals
  - Social pressures, embarrassment around messy eating
  - Extend range of food/fluid textures
  - Posture
  - Challenges to develop more skilled movement
- 

# EDACS to track function

- Used in Deep Brain Stimulation study (Evelina)
  - Before and after interventions such as SDR?
  - Possible adverse events linked to Botox?
  - Relationship to postural change?
  - Pre and post orthopaedic surgery e.g. spinal
  - Uncontrolled epilepsy
  - Other ideas???
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# EDACS to determine intervention

- MDT saliva control clinic at Chailey Clinical Services
  - E.g. EDACS V contra-indication for Sub-mandibular Duct Transposition surgery and botox for sialorrhea
- Dental care and oral hygiene routines by EDACS level (Emanuel et al. 2017)
- Vital stim by EDACS level??
- What interventions are best suited to what level??

# EDACS – research

- Connects clinical practice and research activity
- Adopted by CP surveillance databases
- Compare and generalise results
- Prevalence? Estimates range between 40 – 95% .....
- Identify and test appropriate interventions by EDACS level?
- Prognosis?

# However ....

- EDACS is new
- Research evidence for EDACS clinical applications – limited to non-existent
- New territories to explore .....






# First Steps

# Retrospective study

- Results from retrospective case note review
- First steps to answer some important clinical questions
- “Quick and dirty!”

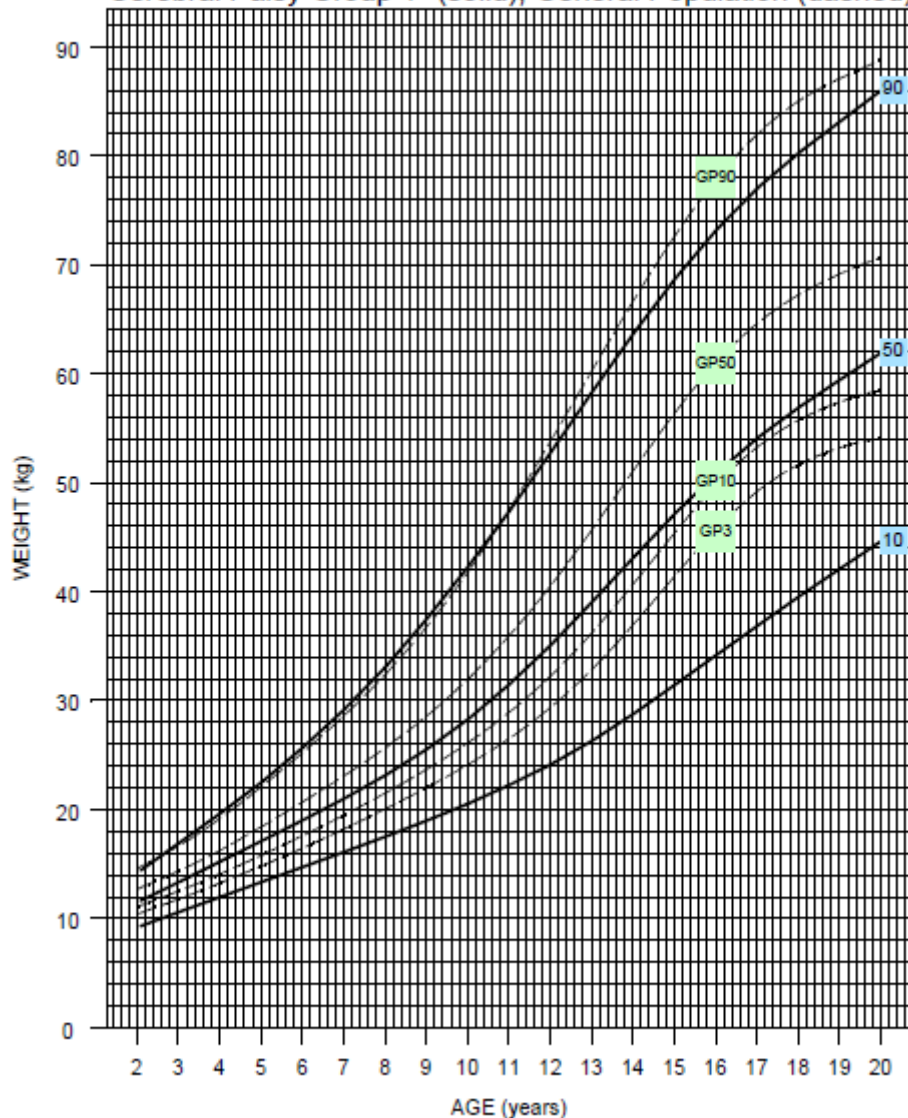


# Clinical questions?

- Is someone's eating and drinking ability (EDACS) closely linked to their ability to sit, stand and move (GMFCS)?
  - What are the links between children's ability to eat and drink and rates of growth?
- 



### Weight-for-age percentiles: Boys 2-20 years Cerebral Palsy Group 1\* (solid), General Population (dashed)



\*Group 1: Walks well alone at least 20 feet, balances well.

# Clinical question?

- Can we predict how a child's eating and drinking ability will change over time?



# Audience questions

## From your experience of children with CP:

1. What are the links between children's gross motor function and eating/drinking ability?
2. What are the links between weight/age centiles + eating/drinking ability for children with CP?
3. Will children's EDACS levels stay the same over time?

# Preguntas


## En su experiencia con niños con PC :

1. ¿Cuál es la relación entre la función motora gruesa y la habilidad para comer y beber?
2. ¿Cuál es la relación entre los percentiles de peso/edad con la habilidad para comer y beber en niños con PC?
3. El nivel de EDACS permanecerá igual en el futuro?

# Retrospective Case Note Review

- Following Wood and Rosenbaum (2000): case note review n=100 children with CP
- Functional abilities using GMFCS, MACS, CFCS, Viking Speech Scale and EDACS at Time Point 1
- GMFCS and EDACS levels at 3 more Time Points. 2 or more years between Time Points

# Retrospective Case Note Review

- Case notes and online records examined reaching back to 2004
  - Standard mealtime guidance format – informing EDACS development
  - Multi-professional reports and assessments
  - Growth charts maintained by Dietitian
- 



## RISKS

Becky gets all the calories and drinks she needs through her gastrostomy. She is at risk of aspirating whenever she eats and drinks. Becky understands this risk and only has tiny tastes of food and drink.

A small group of specially trained people help with tastes. **Do not give Becky anything to eat or drink unless you have been trained.**

**Becky chooses who gives her tastes. Training can be given by Josie Bennett (SALT), Fred Johnson or Rosie Garcia, who have been trained by SALT.**



## Food

Texture – soft chew (see Texture Guidelines)

Becky says:

- *I like tiny tastes of food in the side of my mouth so I can taste flavours that I really like.*
- *Do not put anything in the front of my mouth.*
- *Ask me if I would like something*
- *If yes, break off the tiniest amount (smaller than a currant) and put it in the side of my right cheek.*
- *Give me time to enjoy the flavour and swallow. Do not talk to me*
- *I will look at you when I'm ready for more.*



## Drinks

Consistency – thin fluid (see Texture Guidelines)

Becky says:

- *I like to have tiny flavours of drink put into the side of my mouth. Use tiny syringe for drinks.*
- *Put 1ml of fluid in syringe. Put syringe in the side of my right cheek (not in my mouth). Gently squeeze the syringe to give me the tiniest amount of fluid.*
- *Give me time to get organised to suck and then swallow.*
- *I will look at you when I've finished swallowing then check if I want more.*



## Equipment

- Do not use a cup with Becky.
- Use a small plastic spoon to put the tiniest taste of food in the side of Becky's mouth.
- Use a 1 ml syringe to give Becky tiny tastes of drinks.
- Paper towels to protect clothes



## Position

Becky says:

- *I sit in my wheelchair in the upright position*
- *I need my headrest on.*
- *I need my middle chest strap done up*
- *Sometimes I need my supermarket straps on my wrists. I will tell you when by looking at my wrists.*
- *My assistant needs to stand or sit on a high stool on my right side. You need to be able to see my face clearly.*



## Assistance required

- Give Becky time to adjust her movements to taste food and drink
- Keep calm
- Wait for Becky to swallow and cough if needed. This could take a few minutes.
- When Becky is not ready it does not mean she wants to stop
- Pay close attention to Becky's communication signals.
- Becky chooses if she tastes food/drink.
- Ask Becky if she wants her face wiped

Tastes can take between 5 and 30 minutes.



## Environment

Becky needs a quiet, predictable environment to taste food and drink.

People need special training to assist her.

**People who have been trained are:**

**Rosie Garcia  
Fred Johnson  
Jane McDonald  
Amanda Loughton  
Nicky Burrows  
Harriet Martin**



## Likes

**Becky says:**

- *Foods that work well for me include: the tiniest piece of soft cake, ¼ of a chocolate button, cream, yogurt, tiny crumb of cheese/ soft cheese.*
- *I also enjoy segments of lemon, lime and oranges. Hold the segment between my lips so I can suck the juice out.*
- *Some of the drinks I enjoy include: orange squash, coke.*



## Dislikes

**Becky says:**

- *I will tell you what I like and don't like*
- *I don't like it if you ask my friends questions about me*
- *I don't like it if you use a spoon or a cup at the front of my mouth as this makes me move my tongue backwards and forwards really quickly so I really can't swallow anything*
- *I don't like it if you miss my communication signals*



## Communication

**Becky says:**

- *I understand everything you say – don't talk to me as if I'm a baby*
- *Ask me if you're not sure*
- *I say YES by nodding my head and NO by shaking my head*
- *I have a CCS book. Read instructions in the front to know how to use it*
- *I have a Tellus communication aid*
- *I find it hard to swallow and communicate so don't ask me questions when I am swallowing*
- *I will look at you when I have finished and am ready to chat*



## Things to look out for

**Look out for coughing, panicked facial expressions, changes in skin colour, gurgly voice, chest infections.**

**Contact the SALT if you are concerned or observe any of these things.**



## Contact details

**Josie Bennett – SALT**  
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**Chailey Clinical Services**

This information is written for use at Chailey Heritage Foundation by staff who have attended Eating and Drinking training provided at Chailey Clinical Services



**Date: 7.9.2017**

# Retrospective Case Note Review

- Rater 1 recorded children's functional abilities using functional classification systems at Time Point 1
- Rater 2 assigned EDACS levels for 25 randomly selected children at all time points
- Reliability assessed using ICC
- Recorded weights / age at 4 Time Points where available

# Results

<b>Demographic Information</b>	<b>n=100 children (50 males)</b>
Age range	Time Point 1 2yrs – 17yrs mean 8.55y SD 3.96 Time Point 4 7yrs – 26yrs mean 16.06y SD 4.33
Gastrostomy / enterally fed	49
Orthopaedic issues	85
Seizures	65
Reflux	56
CP Subtype (SCPE)	55 spastic bilateral (including mixed presentation) 34 dyskinetic 1 spastic unilateral 10 non-classifiable
GMFCS levels Time Point 1	I 3 II 1 III 10 IV 44 V 42

# Results

## Reliability:

- Rater 1 vs Rater 2: ICC 0.95 (95%CI 0.91-0.97)
- ICC values  $> 0.9$  indicate excellent reliability / agreement

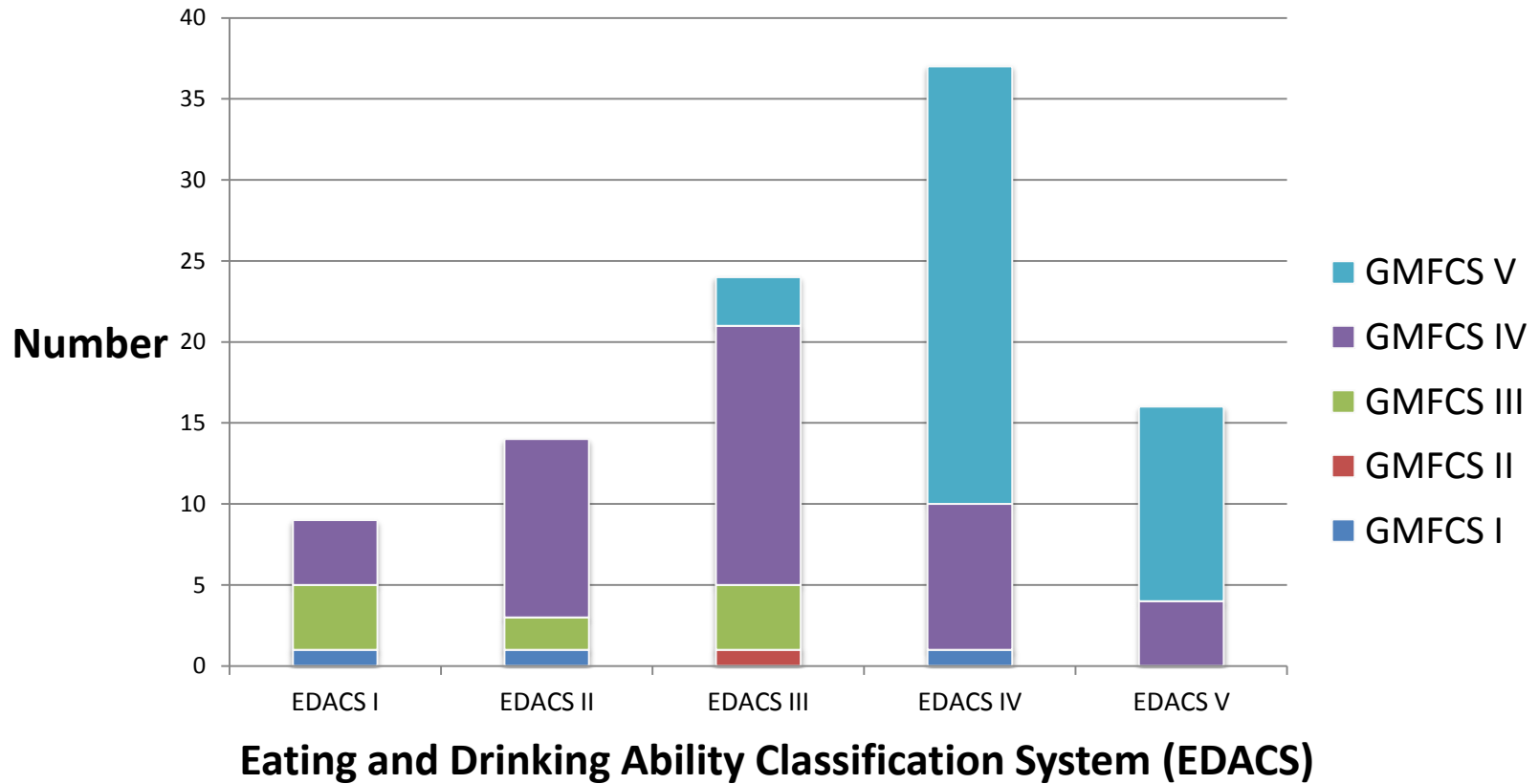
# Question 1

What is the link between children's gross motor ability (GMFCS Levels I - V) and eating + drinking ability (EDACS levels I – V)?

1. No link
2. EDACS levels sometimes same as GMFCS levels
3. EDACS levels mostly same as GMFCS levels
4. EDACS levels always same as GMFCS levels
5. Unsure

# Results

## Children's eating and drinking ability (EDACS) and gross motor function (GMFCS)



Significant moderate positive correlation between EDACS and GMFCS (Kendall's Tau<sup>b</sup> =0.6 p<0.001)

# Results

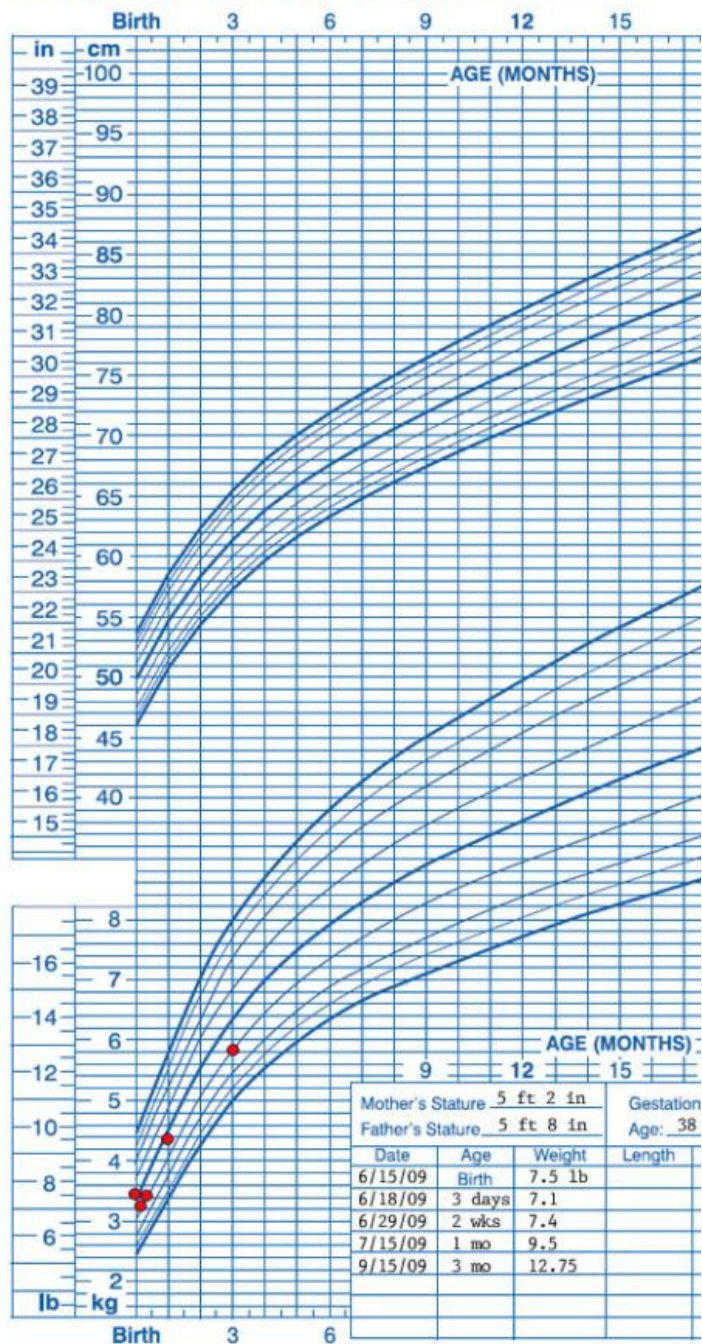
Associations between different areas of function

- Eating/drinking and manual ability
  - EDACS vs MACS  $\tau^b = 0.7$   $p < 0.001$
- Eating/drinking and speech
  - EDACS vs Viking Speech Scale  $\tau^b = 0.7$   $p < 0.001$
- Eating/drinking and communication
  - EDACS vs CFCS  $\tau^b = 0.5$   $p < 0.001$

# Birth to 24 months: Boys

## Length-for-age and Weight-for-age percentiles

NAME \_\_\_\_\_

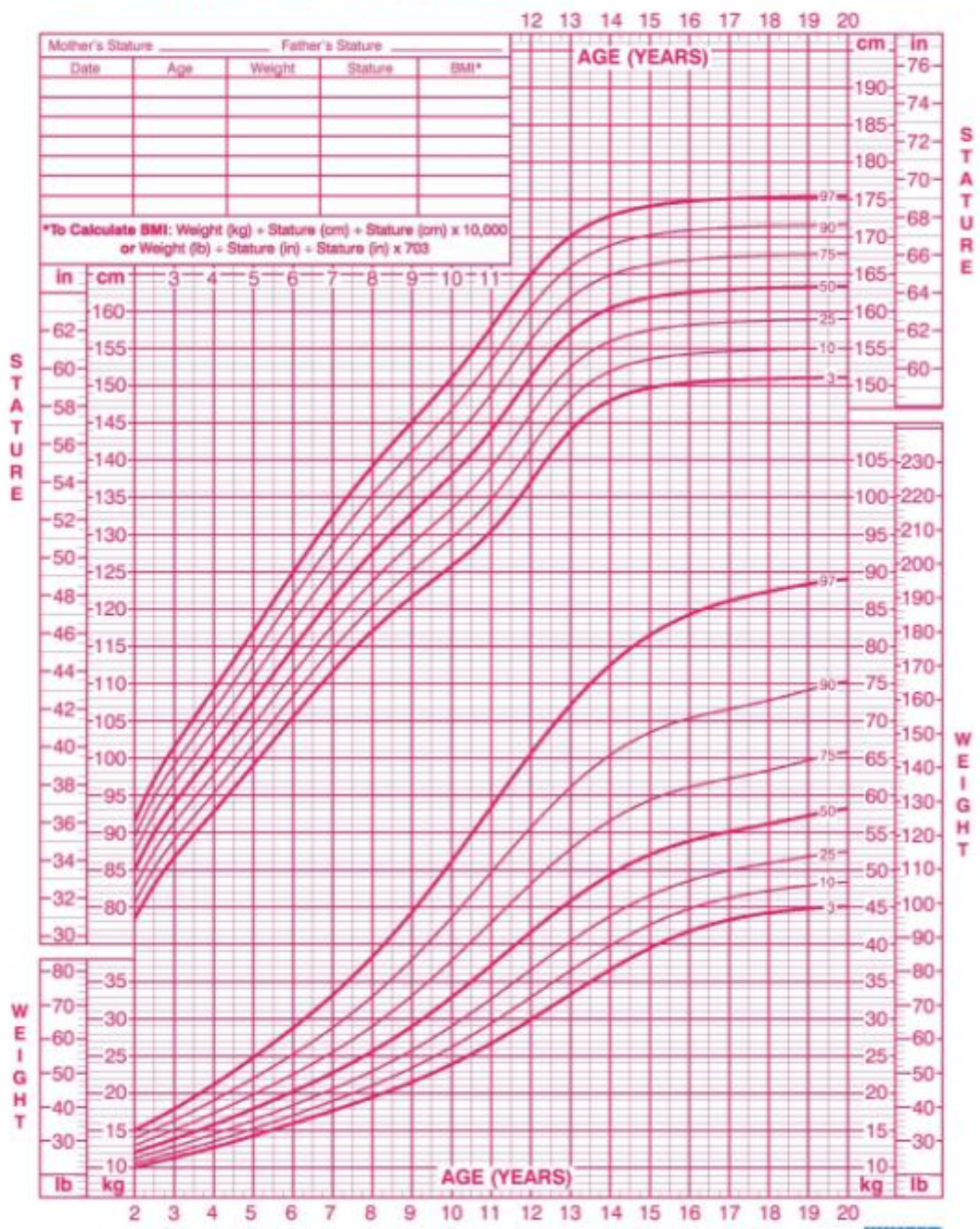


# 2 to 20 years: Girls

## Stature-for-age and Weight-for-age percentiles

NAME \_\_\_\_\_

RECORD # \_\_\_\_\_



# Question?

What are the links between weight-for-age centile and EDACS levels I – II for children with CP (no tube-feeding)?

1. Normal spread across centiles
2. EDACS levels I – II  $\Leftrightarrow$   $<0.4^{\text{th}}$  –  $25^{\text{th}}$  centiles
3. EDACS levels I – II  $\Leftrightarrow$   $25^{\text{th}}$  –  $75^{\text{th}}$  centiles
4. EDACS levels I – II  $\Leftrightarrow$   $75^{\text{th}}$  -  $>99^{\text{th}}$  centiles
5. Unsure

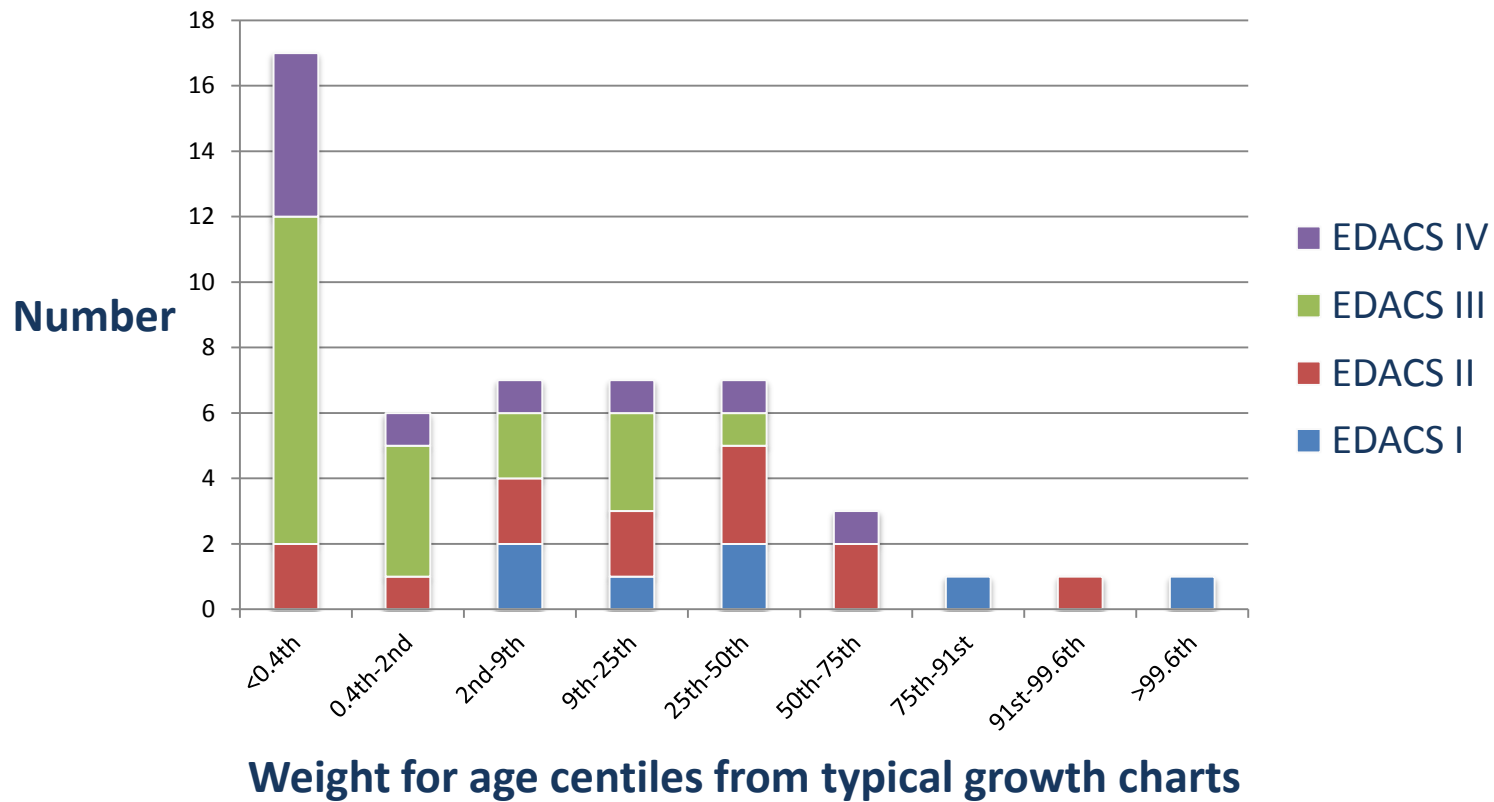
# Question?

What do you think the links are between weight-for-age centile and EDACS levels III – IV for children with CP (no tube-feeding)?

1. Normal spread across centiles
2. EDACS levels III – IV  $\Leftrightarrow$   $<0.4^{\text{th}}$  –  $25^{\text{th}}$  centiles
3. EDACS levels III – IV  $\Leftrightarrow$   $25^{\text{th}}$  –  $75^{\text{th}}$  centiles
4. EDACS levels III – IV  $\Leftrightarrow$   $75^{\text{th}}$  –  $>99^{\text{th}}$  centiles
5. Unsure


# Results

Number of children within each weight-for-age centile group at **Time Point 1**, by EDACS level



# Question?

What changes in EDACS levels would you expect over time for most children with cerebral palsy?

1. Stay the same
  2. Change by up to 1 level
  3. Change by up to 2 levels
  4. Change by up to 3 levels
  5. Change by up to 4 levels
  6. Unsure
- 

# Results

- **Stability of EDACS over time:**
  - ICC 0.97 (95%CI 0.96-0.98)
  - EDACS levels remained stable although children changed how they used underlying abilities
- **EDACS changes over time:**
  - 15/100 changed by 1 level
  - 3 /15 improved function from Level IV to Level III
  - 10 /15 lost function by 1 level between 12 and 19yrs
  - 11 /12 who lost function had orthopaedic issues and/or seizures (7 children GMFCS V; 4 children GMFCS IV)

# Cases

- **Case 1.** Female (GMFCS I, MACS I, VSS III, CFCS III at TP 1). EDACS Level IV to III between 3-6yrs with acquisition of biting / chewing / drinking skills.
- **Case 2.** Male (GMFCS V, MACS V, VSS IV, CFCS V at TP1). EDACS Level IV to V between 17-19yrs with progressive scoliosis and other orthopaedic issues. Aspiration of food/drink on VFSS.
- **Case 3.** Female (GMFCS III, MACS III, VSS III, CFCS III at TP1). EDACS Level III stable from 5yrs to 14yrs. Major concerns about weight at age 5; no concerns at 14yrs as eating more efficiently.

# Emma's Story

- Typical gross motor development
- No speech at 3 years
- Eating and drinking issues with weaning
- Diagnosis of Worster Drought Syndrome – 4yrs

# Emma's Story

- **Gross Motor Function: I** Walks without limitations
- **Manual Ability: I** Handles objects easily and successfully
- **Communication Function: III** Effective sender & receiver with familiar partners; changing to **II** effective sender and receiver information with familiar and unfamiliar partners but may need extra time
- **EDACS IV to III:** Change at 3;06 with introduction of soft chew textures



# Conclusions



- Children's EDACS levels appear stable over 6yrs or more
- Most changes in EDACS levels occurred in adolescence
- Preliminary evidence to support use of EDACS to predict limits of change in eating/drinking ability
- Prospective longitudinal studies required

# EDACS

- Classifies eating and drinking performance of people with CP from age 3 years
- Useful in clinical and research contexts
- 14 / 25 completed language translations including **Spanish**, Dutch, German, Arabic, Farsi, Hebrew, Norwegian, Chinese
- Free to download from [www.EDACS.org.uk](http://www.EDACS.org.uk)

# EDACS – further developments

- Further psychometric properties: Monbaliu et al.(2017), Benfer et al.(2017), Tschirren et al.(2018), van Hulst et al.(2018)
- EDACS accepted as Functional Classification System for CP
- Used by international CP surveillance registers and research groups
- Preliminary study of stability over time – Sellers et al. (2017)
- Mini-EDACS 18 - 36 months currently in development

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- Any questions or comments?
  - Email: [diane.sellers@nhs.net](mailto:diane.sellers@nhs.net)
  - Website: [www.edacs.org](http://www.edacs.org)
- 

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# EDACS

EATING AND DRINKING ABILITY  
CLASSIFICATION SYSTEM