

chailey
clinical
services



NHS

Sussex Community
NHS Foundation Trust

Development, reliability, utility of EDACS in children with cerebral palsy

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Chailey Clinical Services



Excellent care at the heart of the community

EDACS

- Eating and Drinking Ability Classification System
- Sellers et al. 2014 DevMedChildNeuro
- www.edacs.org

Overview


- Background
- Methods
- Content
- Reliability
- Utility

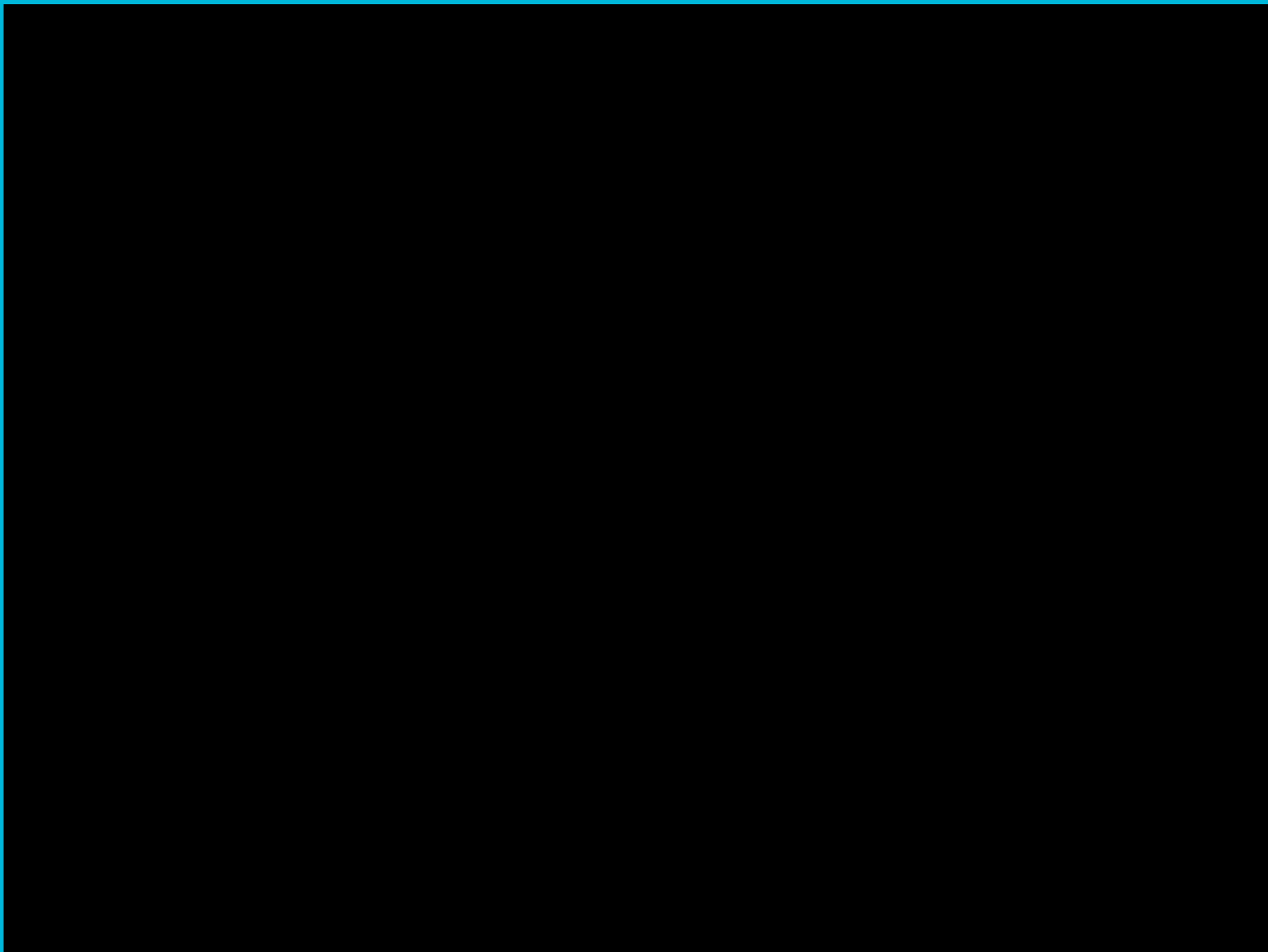


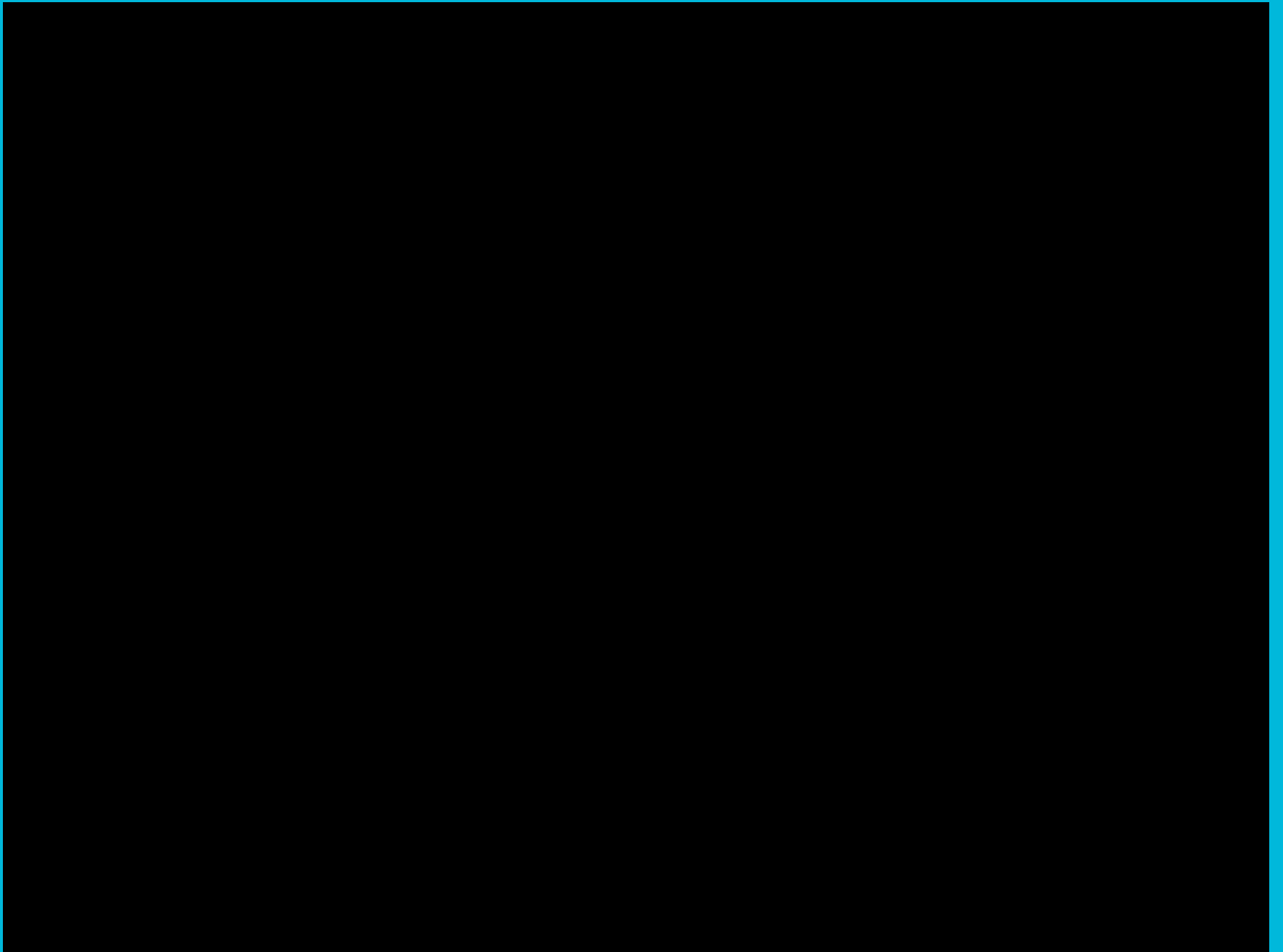


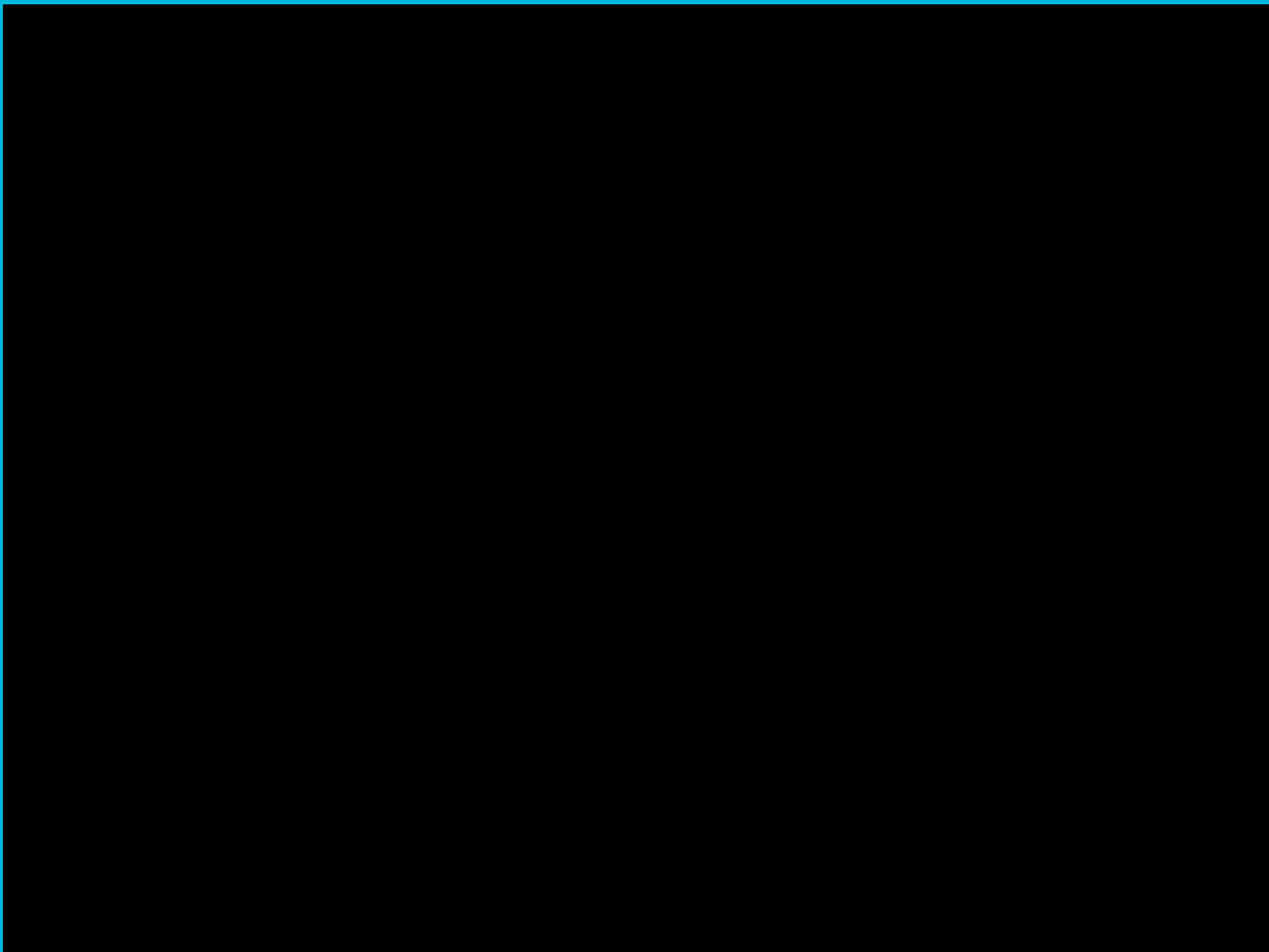
Cerebral Palsy

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
- 







Origins of EDACS

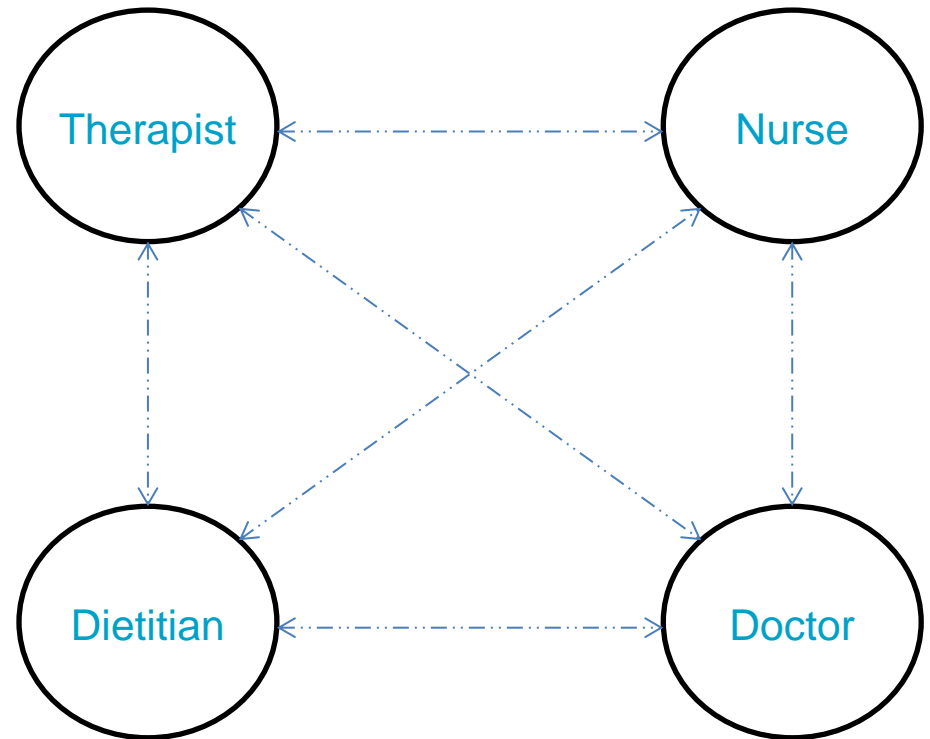
Nutrition Team providing clinical care to children and young people with complex physical disability:
Paediatrician, Dietitian, Nutrition Nurse Specialist,
Speech and Language Therapist



Team working

Each member has different:

- Professional training
- World view
- Roles
- Responsibilities
- Interests
- Styles
- Language and jargon
- Frameworks
- Goals



Questions arising from team...

- Can we simplify descriptions of someone's eating and drinking ability?
- What are the key features of eating and drinking ability that all team members need to know about?
- Is there a means to classify eating and drinking ability to show one child's ability is more limited than another's?

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)

Adult Services

Acute Hospitals

Social Services

Research

Specialist Surgery:
orthopaedic,
gastrostomy, ENT etc.

Specialist NHS
services

Other schools

Respite care

Nutrition Team

Commissioners

GPs

Community
NHS services

Other Chailey
Heritage Clinical
Services teams

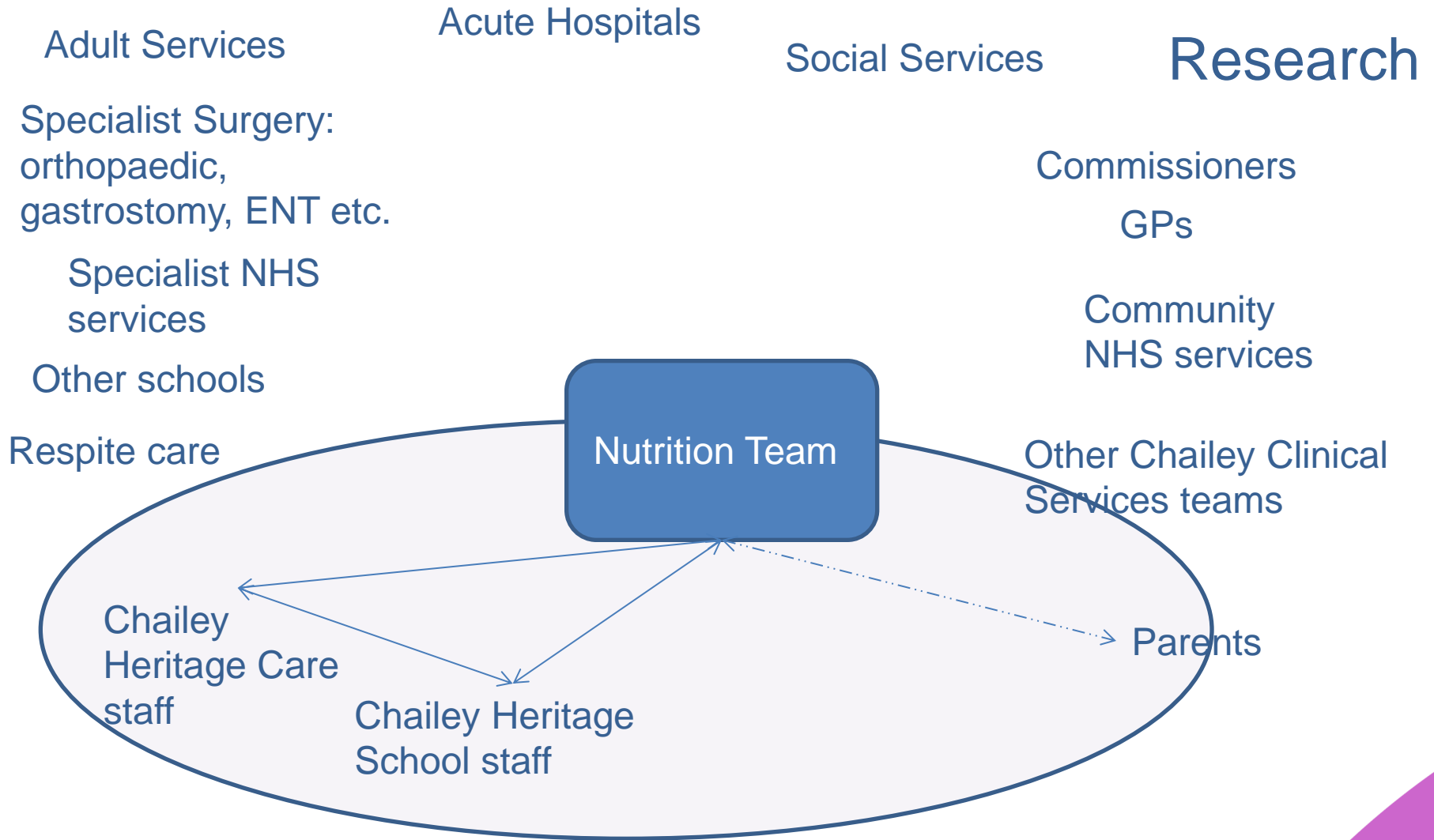
Chailey
Heritage Care
staff

Chailey Heritage
School staff

Parents



Local solution ...



But not this ...

Acute Hospitals

Adult Services

Social Services

Specialist Surgery:
orthopaedic,
gastrostomy, ENT etc.

Commissioners

GPs

Specialist NHS
services

Community
NHS services

Other schools

Child with
cerebral palsy
and family

Respite care

Other Chailey
Heritage Clinical
Services teams

Research


Chailey
Heritage Care
staff

Chailey Heritage
School staff

Nutrition Team



Wider questions

- Can we predict how eating and drinking ability will change over time?
 - Is there a validated tool to measure eating and drinking for use by parents?
 - What are the links between children's ability to eat and drink and rates of growth?
 - What is the prevalence of eating and drinking difficulties in population of people with cerebral palsy?
- 

Inspiration from GMFCS

Based on concepts of disability and “limitation in performance at the level of the whole person”

(Nagi 1965)


NOT:

- parts of body most involved
- neuro-anatomical location of lesion
- impairment in muscle tone, voluntary control of activity

(Palisano et al. Dev Med Child Neuro 1997)



Reasons for GMFCS

- Enhance communication among professionals and families
 - Assist in determining needs of child with CP
 - Creation of databases (CP Surveillance)
 - Comparing and generalising results
 - Predictive validity
- 

Health Measurement Scales

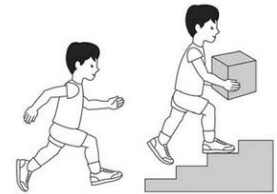
Ordinal Scales – common place

For example:

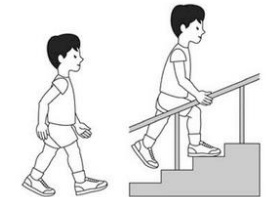
- Tumour Grading Scales (0 – 4)
- Cancer Staging Scales (0, I to IV)
- Injury severity score (1. Minor, 2. Moderate, 3. Serious, 4. Severe, 5. Critical, 6. Unsurvivable)

GMFCS - Summary

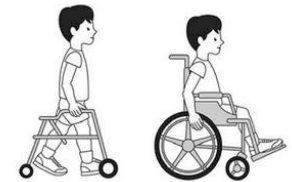
❖ **Level I:** Walks without limitations



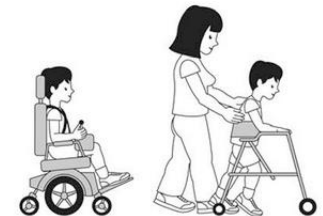
❖ **Level II:** Walks with limitations



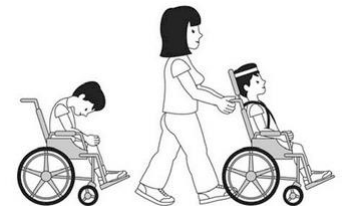
❖ **Level III:** Walks using a hand held mobility device



❖ **Level IV:** Self-mobility limitations; may use powered mobility



❖ **Level V:** Transported in a manual wheelchair



GMFCS

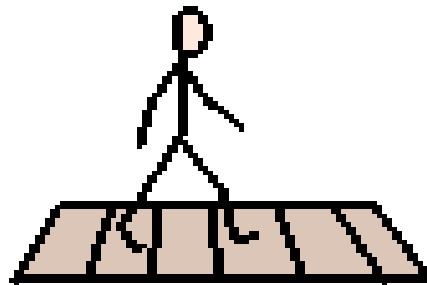
- Standardises severity ratings of gross motor ability.
- Replaces terms such as “mild”, “moderate” and “severe impairment” which lack consistent definition.
- Use of such terms dependent upon experience.
- GMFCS is now well established as reliable systematic way of rating gross motor function.

Functional Classification Systems

- Other functional classification systems for people with CP:
 - Manual Ability (MACS Eliasson et al. 2006)
 - Communication Function (CFCS Hidecker et al. 2011)
 - Viking Speech Scale (Pennington et al. 2013)
- Ordinal scales (I – IV or V)
- Measures of extent of limitations to function
- Suitable for use in clinical and research contexts

Audience Question

Are you familiar with the Gross Motor Function Classification System (GMFCS)?



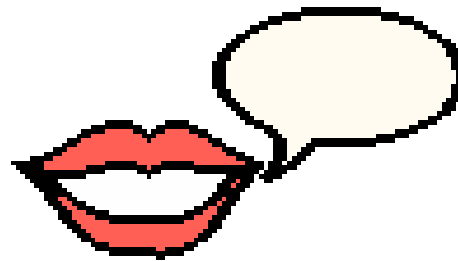
Audience Question

Are you familiar with the Manual Ability Classification System (MACS)?



Audience Question

Are you familiar with the Communication Function Classification System (CFCFS)?



Audience Question

Are you familiar with the Eating and Drinking Ability Classification System (EDACS)?



Functional Classification Systems

Functional Classification Systems **cannot** be used as:

- Outcome Measures
- Diagnostic Tools
- Tests

FCS **do not** replace suitable assessment instruments. Each one simply describes “levels” of functioning within the respective domains.

See Rosenbaum et al. 2014 Journal of Child Neurology **29(8)** 1036-1045

Systematic Review

- Systematic review of ordinal scales used to classify eating and drinking ability of people with CP
- Ordinal scale = descriptions of eating and drinking ability placed in 3 or more ordered categories
- Identified 15 different measures in research literature

Systematic Review

- 13 / 15 scales for clinician / researcher use only
- 9 / 15 scales from parent interviews or questionnaires
- 8 / 15 scales used terms “mild”, “moderate” and “severe” differently
- 5 / 15 scales assessed either content validity and/or reliability
- 0 / 15 scales met psychometric quality standards

Sellers, Pennington, Mandy and Morris (DMCN 2014)

Health Measurement Scale - Quality Definition

Content validity satisfactory if:

- Clear definition of purpose of assessment, target population, concepts being measured
- Content identified with input from target population / experts and investigators

Reliability is considered satisfactory:

- ICC or weighted kappa ≥ 0.7 in sample size ≥ 50 patients

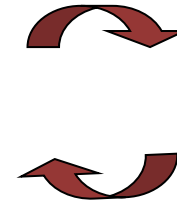
Terwee et al. (2007)

Definition and
evaluation of
content

1. Construct EDACS
draft



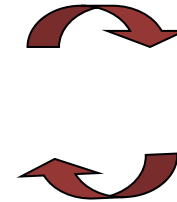
2. Nominal Group
Process



Revise
Draft



3. Delphi Survey



Revise
Draft




4. Reliability
Studies


Evaluation of
reliability when
used by different
observers



Nominal Group Process

- Structured group interaction
 - Group size 10 people or less
 - 7 held around England – 57 participants
 - Multi-professional groups with / without parents
 - Parent group
 - Speech and language therapist group
 - Group discussion by young people with physical disability
- 

Delphi Survey

- 95 participants in Delphi Survey over 2 rounds
 - International group of experts with experience across 5 continents
 - Years experience: range 2y-52y; median 16y
mean 19.6y SD 11.8y
- 


Participants

- Speech & Language Therapists ... 47%
 - Paediatricians ... 14%
 - Parents ... 7%
 - People with CP ... 7%
 - OTs / Physios ... 7%
 - Nurses ... 5%
 - Dietitians ... 4%
 - Other ... 9%
- TOTAL** **n=151**

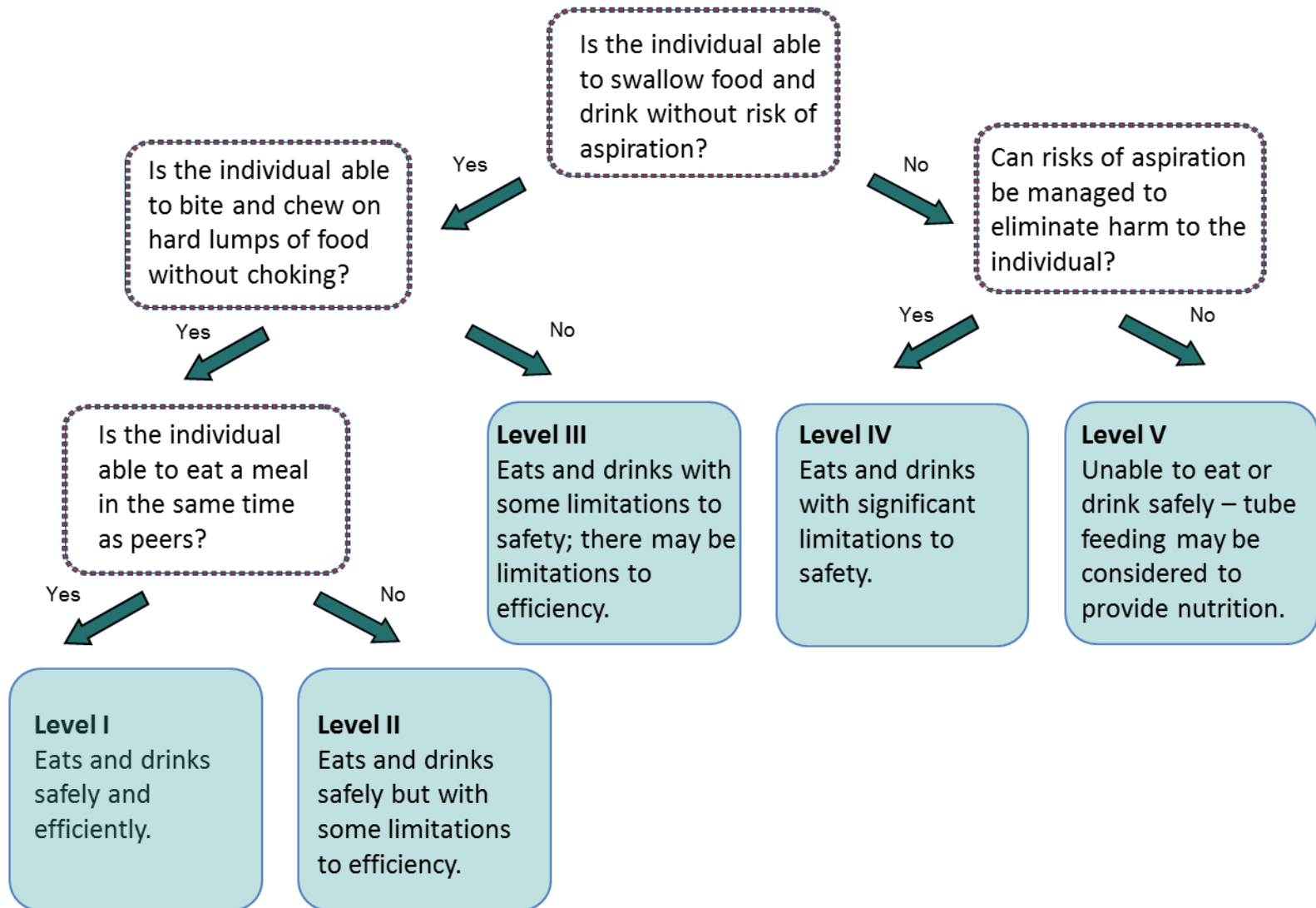
Results: Delphi Survey

Levels of Agreement	≥80%	<80%
Delphi Round 1	39 / 42 statements	3 / 42 statements
Delphi Round 2	5 / 5 statements	0 / 5 statements


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
- 

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.
- 

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.

Inter-observer reliability studies

Paired ratings for 100 children with CP (4 - 22 yrs) by speech&language therapists (SaLTs)

SaLT1 vs. SaLT2 – EDACS:

- Absolute agreement: 78%
- Chance corrected agreement (kappa): 0.72
- ICC (consistency single measures): 0.93 (0.90 – 0.95)

SaLT1 vs. SaLT2 level of assistance:

- Absolute agreement: 87%
- Chance corrected agreement (kappa): 0.80
- ICC (consistency single measure): 0.86 (0.76 – 0.92)


Inter-observer reliability studies

Paired ratings for 48 children with CP (4 – 17 yrs) by SaLTs and parents


SaLT1 vs. parents – EDACS:

- Absolute agreement: 58%
- Chance corrected agreement (kappa): 0.45
- ICC (consistency single measures): 0.86 (0.76-0.92)

SaLT1 vs. parents - level of assistance:

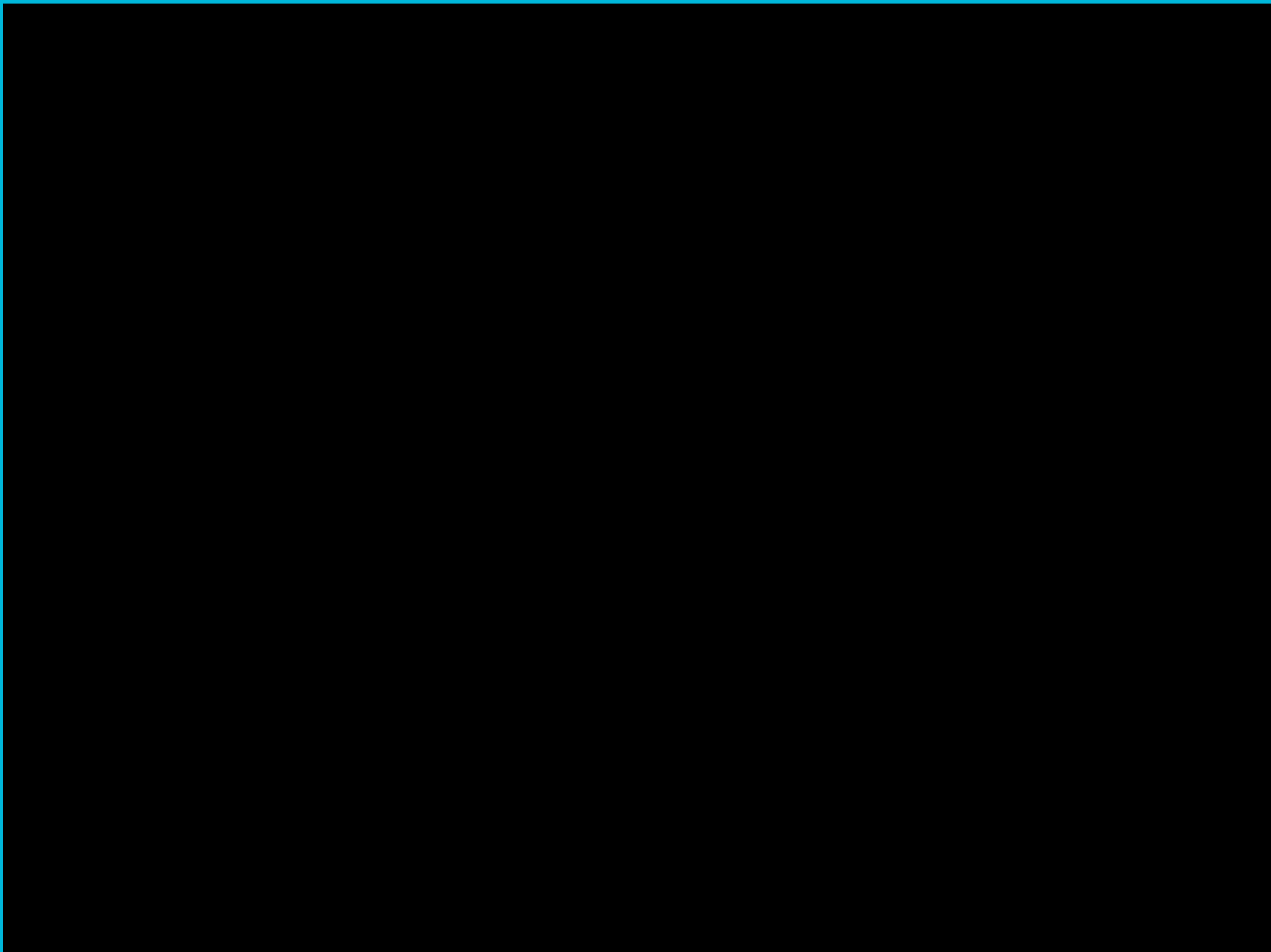
- Absolute agreement: 79%
 - Chance corrected agreement (kappa): 0.64
 - ICC (consistency single measures): 0.77 (0.62-0.87)
- 

User feedback

- Easy to use
 - Parents can recognise their children in descriptions
 - Parents surprised their children had similar difficulties to other children with CP
 - Helped think more about eating and drinking
 - Differences between SaLTS and parents consistent
- 

Case Study 1

- Joanna born 1992 with early diagnosis of CP
- Feeding, eating and drinking issues from birth with frequent chest infections and limited growth
- VFSS age 4 years confirmed silent aspiration for all food and fluid textures
- All nutrition via NG or gastrostomy since 1996
- Oral tastes for pleasure and social participation only



Description of function

- **GMFCS V:** Transported in a manual wheelchair
- **MACS V:** Does not handle objects and has severely limited ability to perform even simple actions
- **Viking IV:** No understandable speech.
- **CFCS III:** Effective Sender and Receiver with familiar partners. VOCA user.

EDACS: level of assistance required?

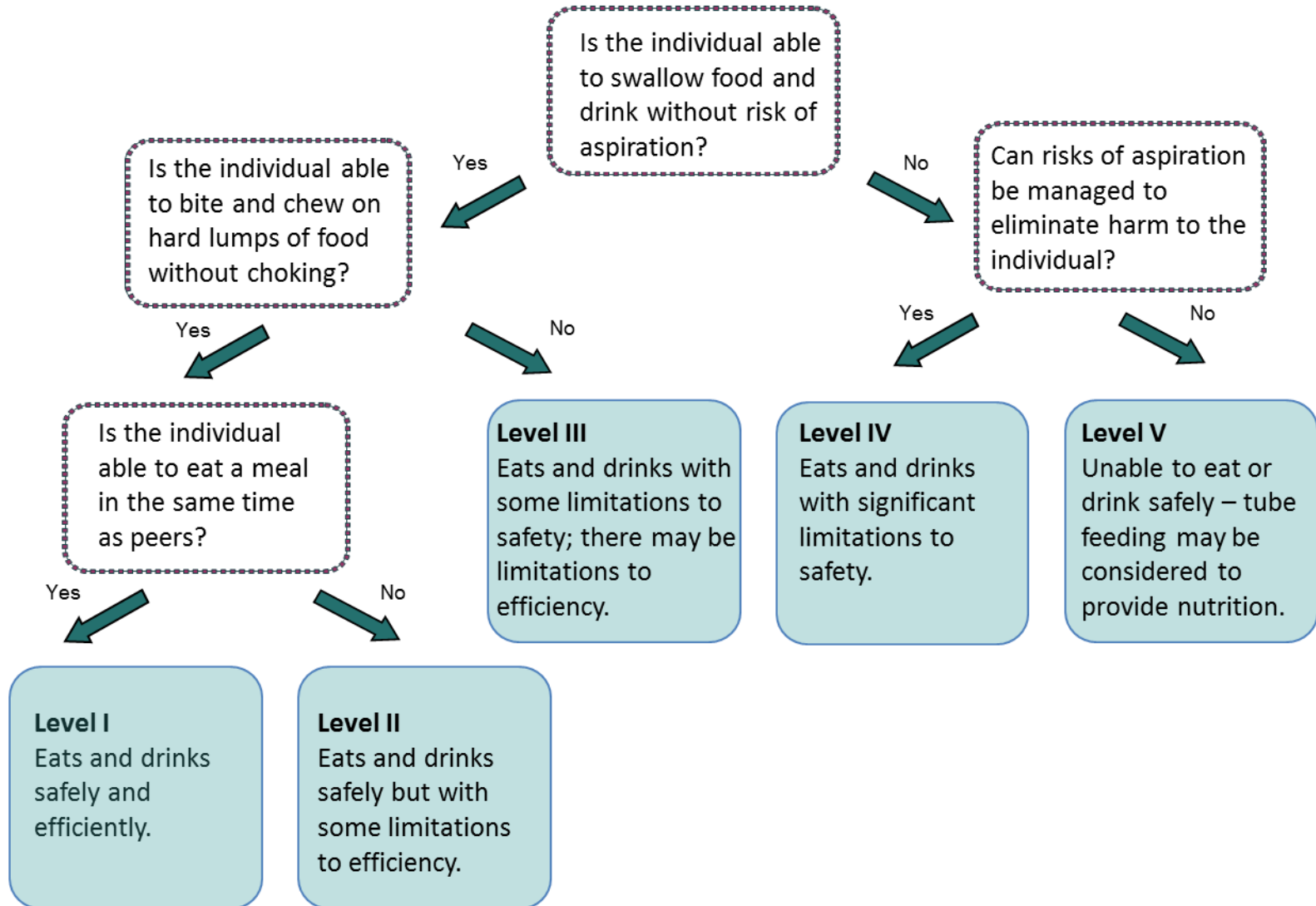
Totally Dependent

Evident harm from aspiration

- Feeding, eating and drinking issues from birth with **frequent chest infections** and limited growth
- VFSS age 4 years confirmed **silent aspiration** for all food and fluid textures
- Oral tastes for pleasure and social participation only

High aspiration risk that cannot be eliminated

Eating and Drinking Ability Classification System

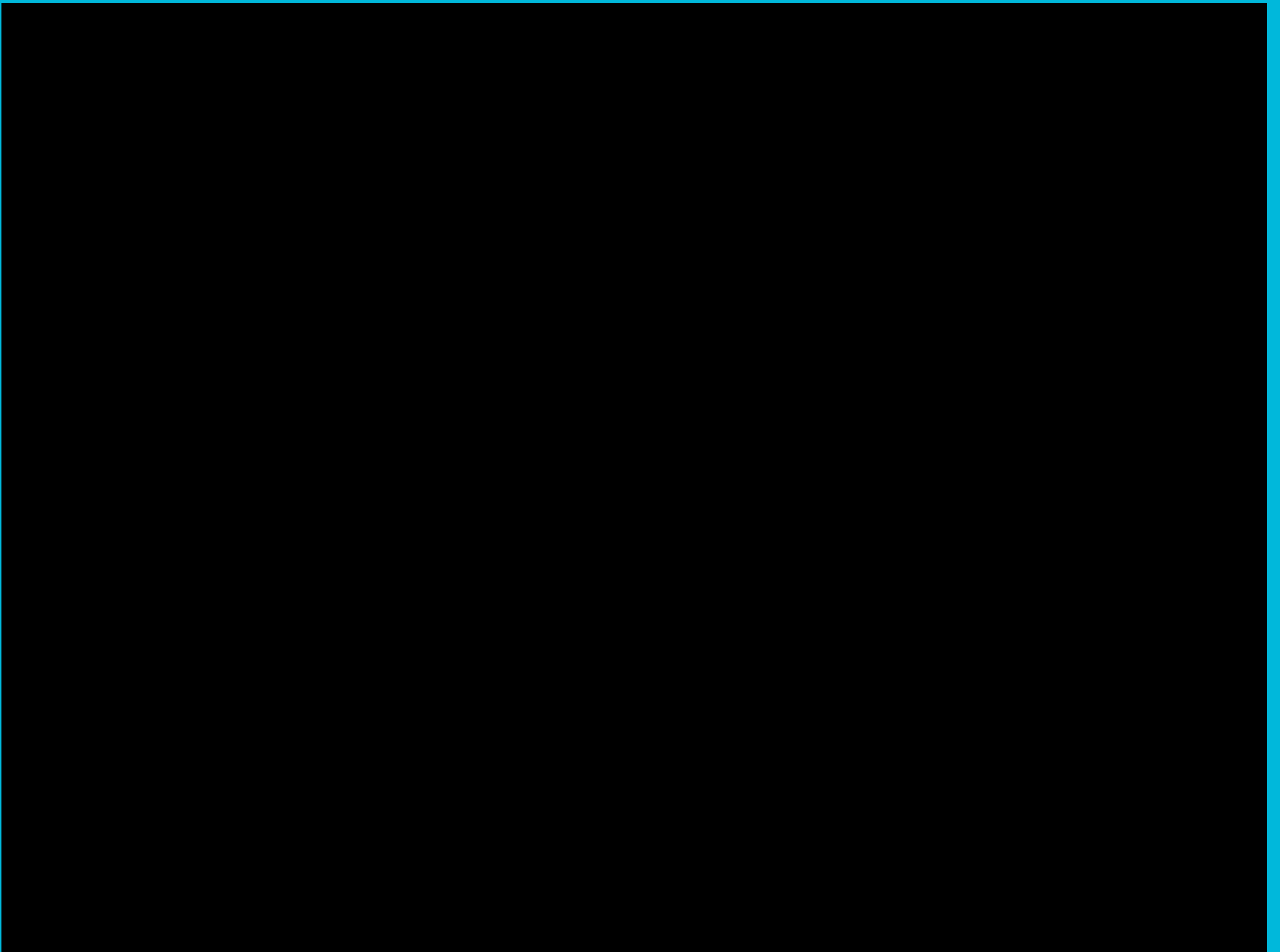


EDACS V: Unable to eat or drink safely – tube feeding may be considered to provide nutrition




Case Study 2

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



Description of function

- **GMFCS I:** Walks without limitations
 - **MACS I:** Handles objects easily and successfully
 - **Viking II:** Speech is imprecise but usually understandable to unfamiliar listeners
 - **CFCS II:** Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners.
- 

EDACS: level of assistance required?

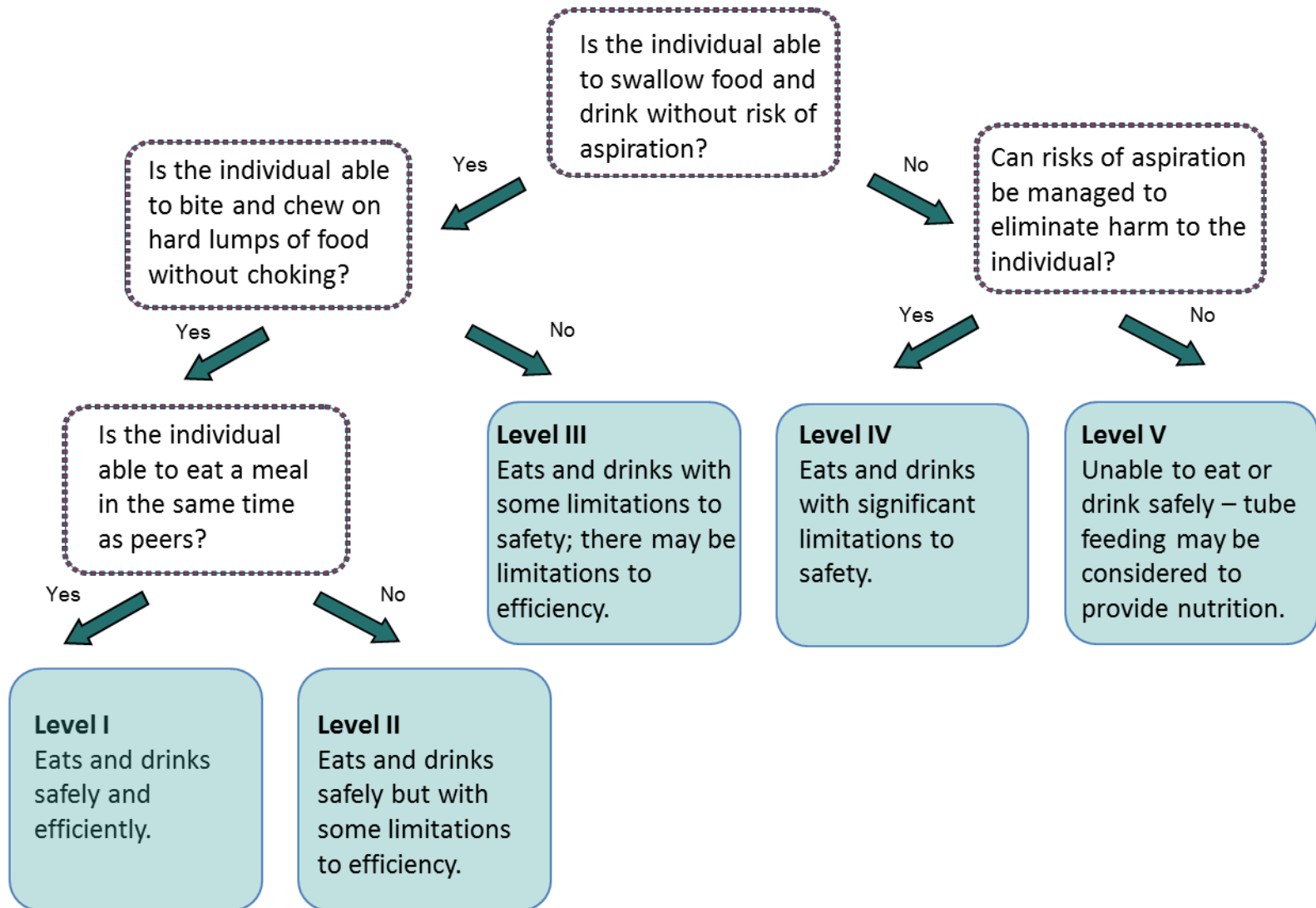
Independent

Chokes on hard lumps of food

- Feeding, eating and drinking issues with weaning
- Choking on hard food textures that require chewing
- Chews soft food textures if placed between molars
- Needs to pay attention when drinking thin fluids from an open cup to avoid coughing – prefers spouted beaker which slows fluid flow rate

Risk of aspiration can be managed and reduced

Eating and Drinking Ability Classification System



EDACS III: Eats and drinks with some limitations to safety; there may be limitations to efficiency

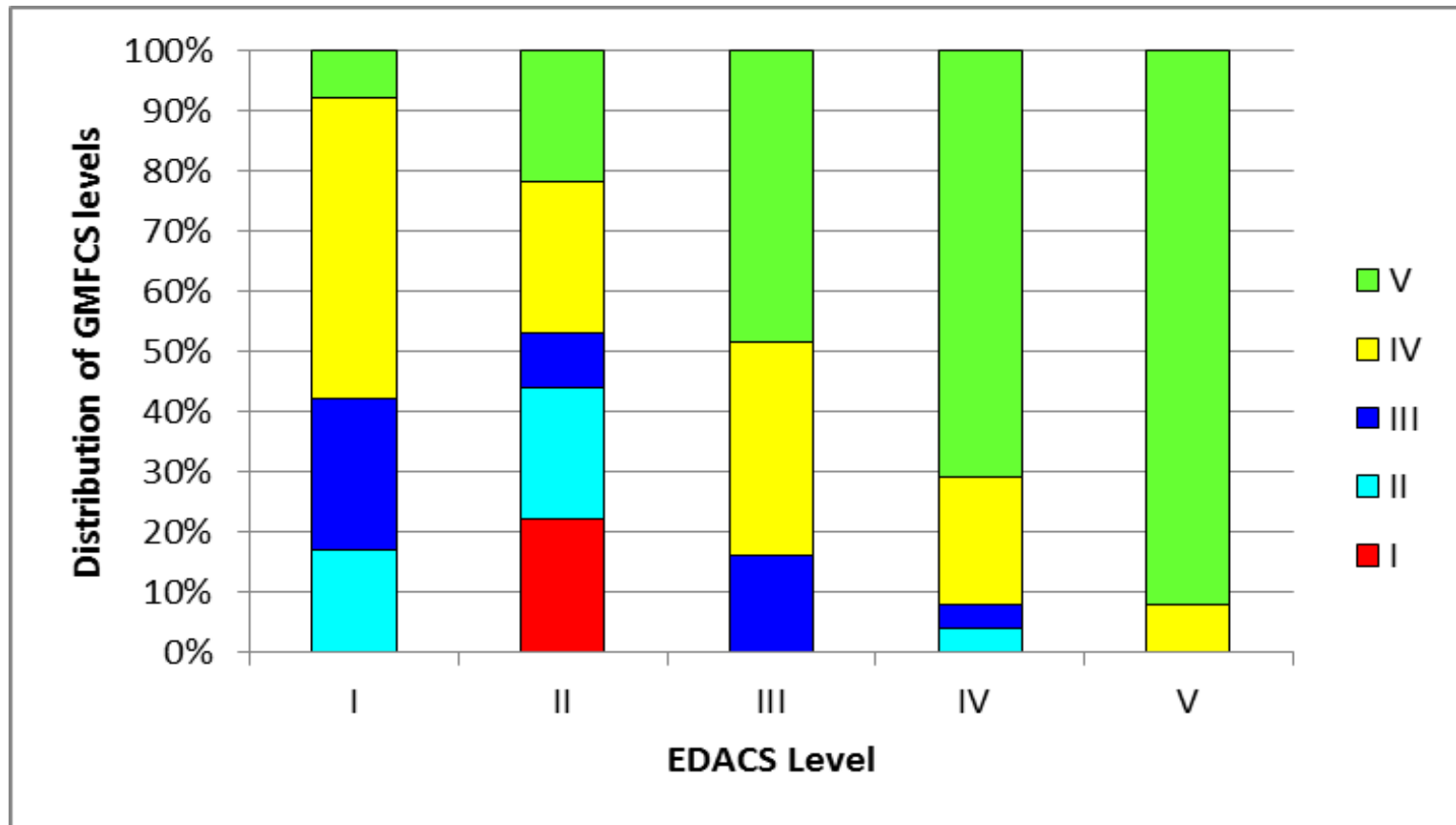


Further results - 128 children

- Incidence of tube feeding increased with EDACS levels although present at EDACS levels I to III
- Significant positive correlation between EDACS level and level of assistance – (Kendall's Tau = 0.69, $p < 0.01$)
- Significant but moderate positive correlation between EDACS and GMFCS – (Kendall's Tau = 0.5, $p < 0.01$)
- Increased incidence of seizure activity with increasing limitations to eating and drinking ability

GMFCS vs EDACS

Eating and drinking ability distinct from gross motor ability





Significant but moderate positive correlation between EDACS and GMFCS (Kendall's Tau=0.5, $p < 0.01$)

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

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 Systems 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

- 
- Any questions or comments?
 - Email: diane.sellers@nhs.net
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- 

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EDACS

EATING AND DRINKING ABILITY
CLASSIFICATION SYSTEM