



# Feeding and Nutrition in the Child with Neurodevelopmental Disabilities

Peter B. Sullivan  
University of Oxford

The Paul Polani Lecture  
Derby, March 2010



# Paul Polani

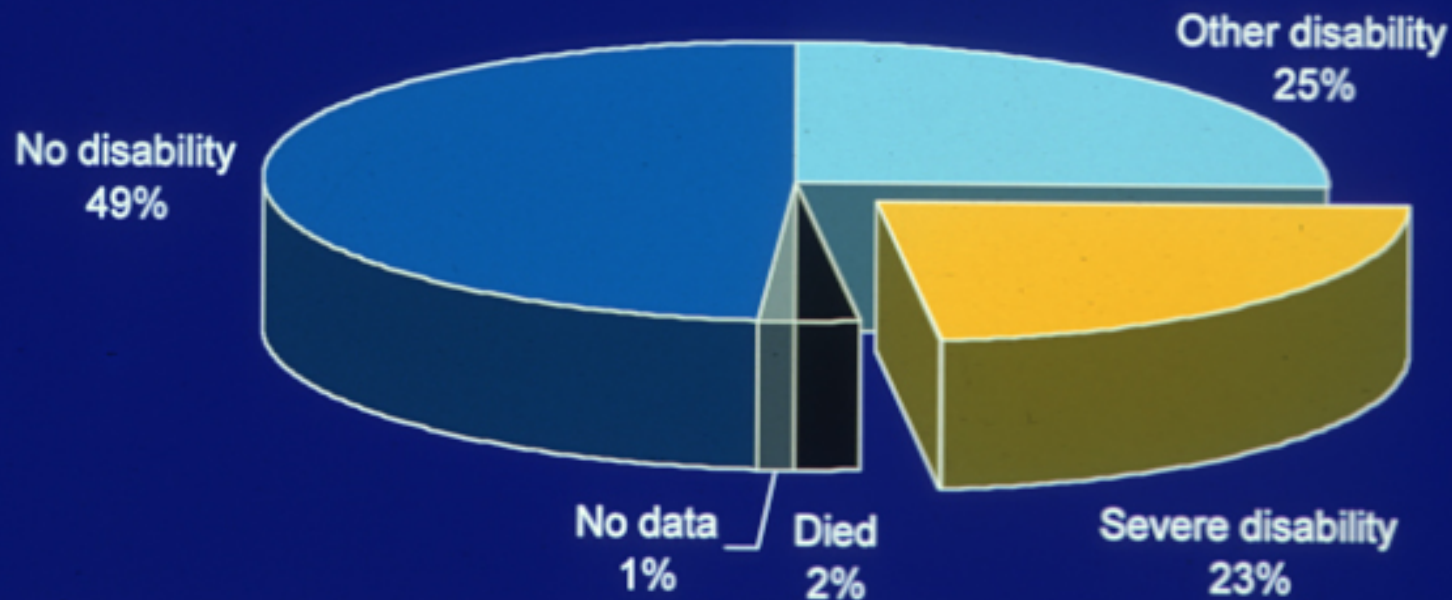
(1914-2006)



*Neonatal encephalopathy,  
Neurodisability and ENS dysfunction*

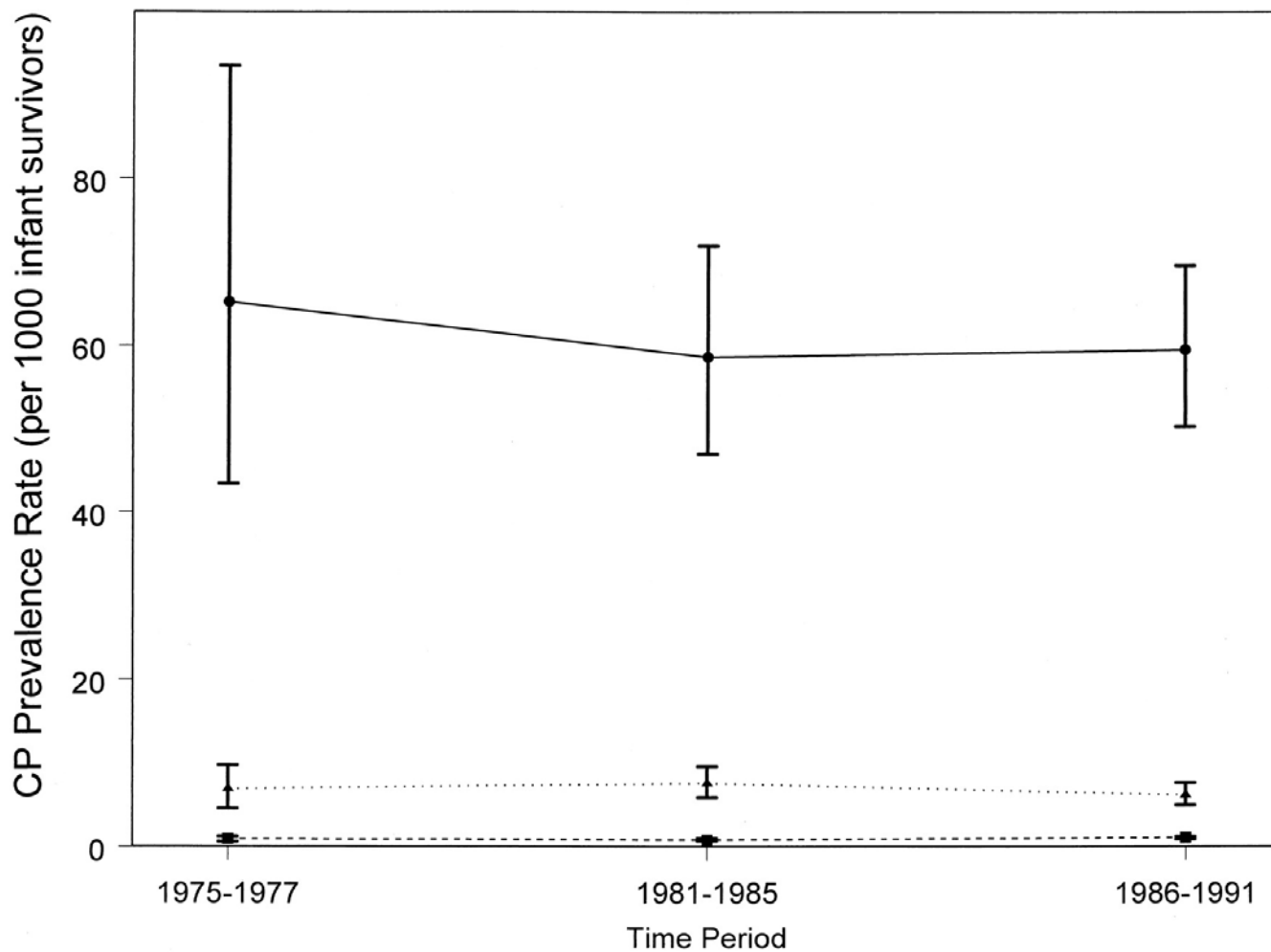


## Disability at 30 months for 314 children born at 22 – 25 weeks gestation



Range of ability found in premature babies in a recent study  
*New England Journal of Medicine (2000;343:378-84)*

**Filled circles indicate <1500 g; filled triangles indicate 1500-2499 g; filled squares indicate 2500+ g**



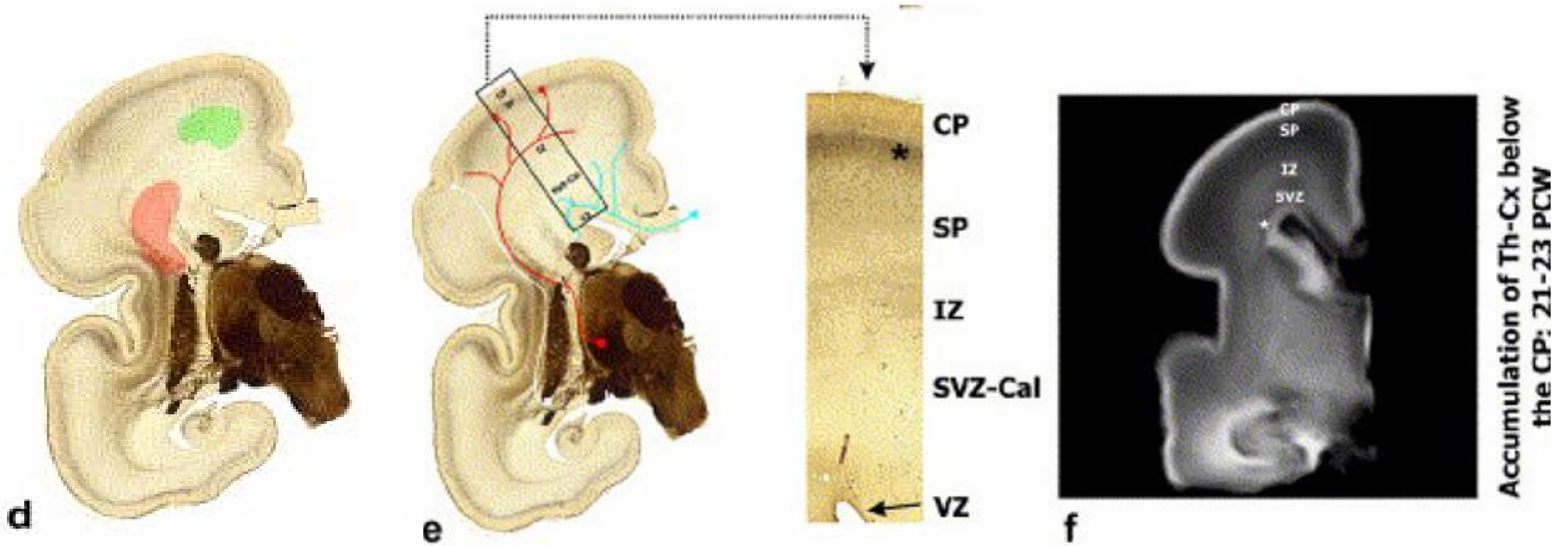
**Winter, S. et al. Pediatrics 2002;110:1220-1225**

**PEDIATRICS®**

The development of cerebral connections during the first 20-45 weeks' gestation.

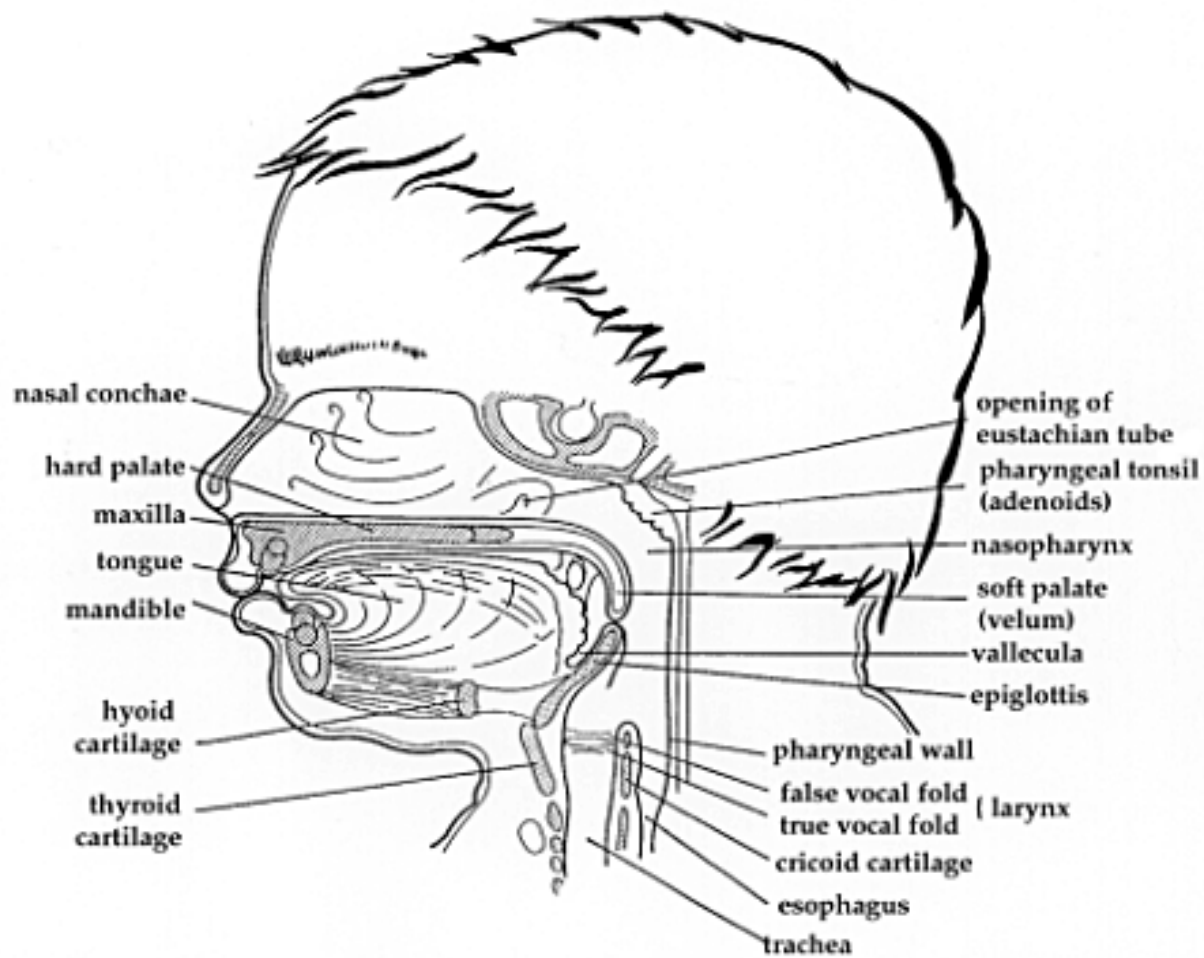
*Kostovic I and Jovanov-Milosevic N.*

*Semin.Fetal Neonatal Med. 11 (6):415-422, 2006*



# THE MOUTH AND PHARYNX OF THE NEWBORN

(saggital section)



# Oral motor dysfunction & feeding inefficiency

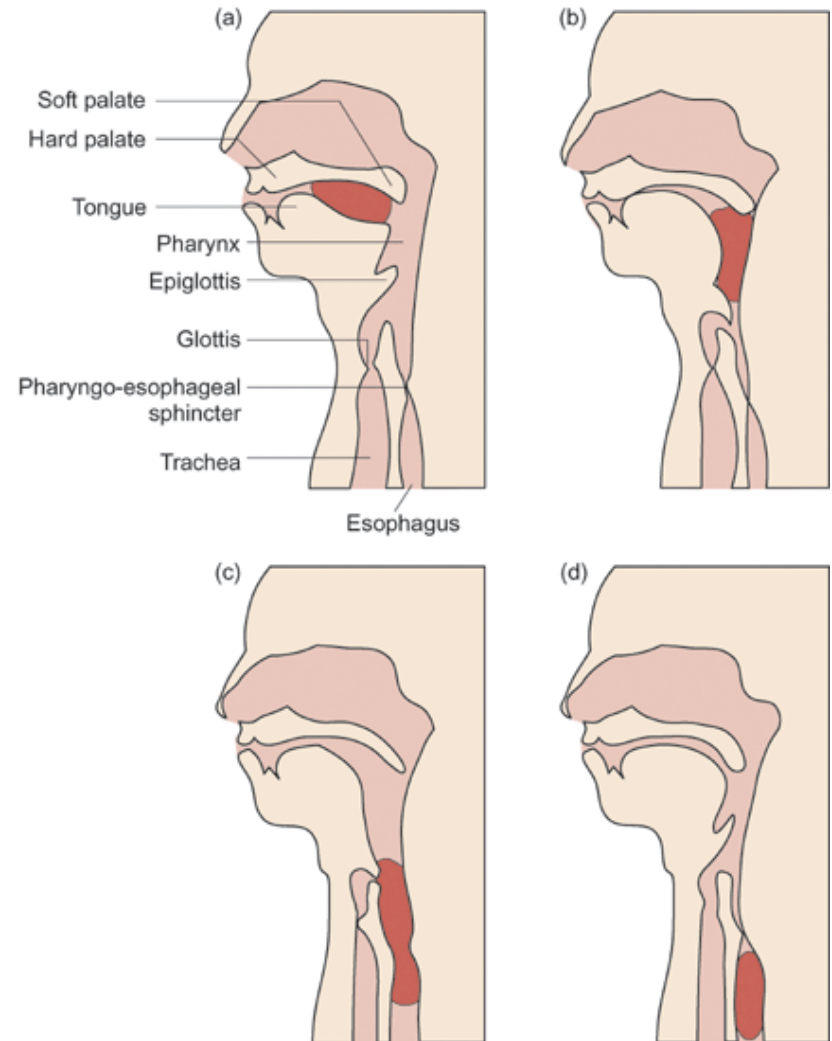
- Poor lip closure
- Excessive drooling
- No tongue lateralisation
- Lip retraction
- Tongue thrusting
- Tonic biting
- Uncoordinated swallowing
- Choking
- Coughing



# Oral motor dysfunction & feeding inefficiency

Significantly reduced nutritional intake

- Oro-pharyngeal incoordination
  - Slow rate of feeding
  - Prolonged feeding times
  - Spillage (>50%)
  - Unsafe swallow
- Vomiting
- Poor dentition
- Early satiety
- Communication deficit
- Behaviour disturbance
  - Food refusal
- Patient:Caregiver ratio



# Consequences of Malnutrition

- ↓ Cerebral function
  - Reduced potential
  - Reduced responsivity
- ↓ Immune function
  - ↑ Infection (chest, UTI)
- ↓ Circulation time
  - ↓ Healing (esp. pressure sores)
- ↓ Respiratory muscle strength
  - Weak cough
  - More chest infections
- Anorexia
- Lethargy
- **Growth failure**

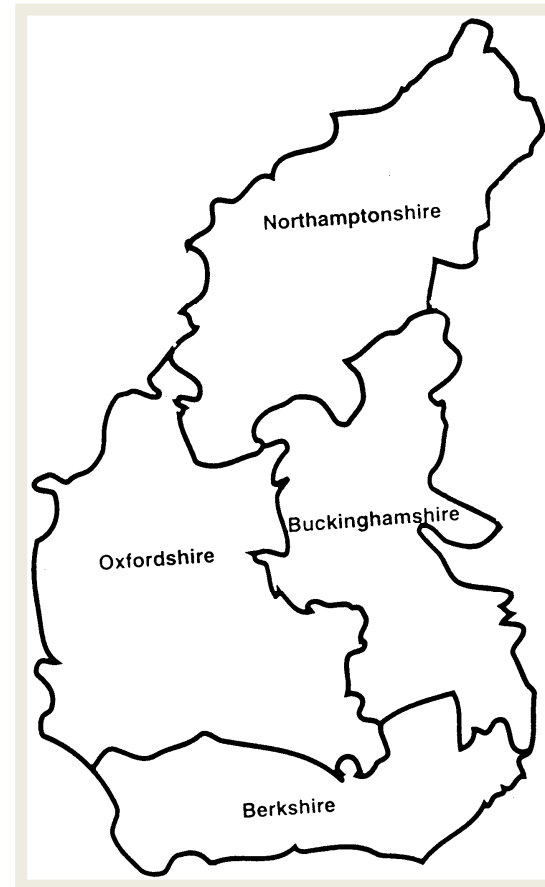


# Nutrition and the disabled child

- Growth and nutritional deficits
  - unrecognised
  - considered to be irremediable
  - low priority
  - Prevalence ?

# THE OXFORD FEEDING STUDY: Methods

- **Oxford Register of Early Childhood Impairment**
  - $n > 800$
  - cerebral palsy
  - born in 4 counties
  - 1984 - 1995

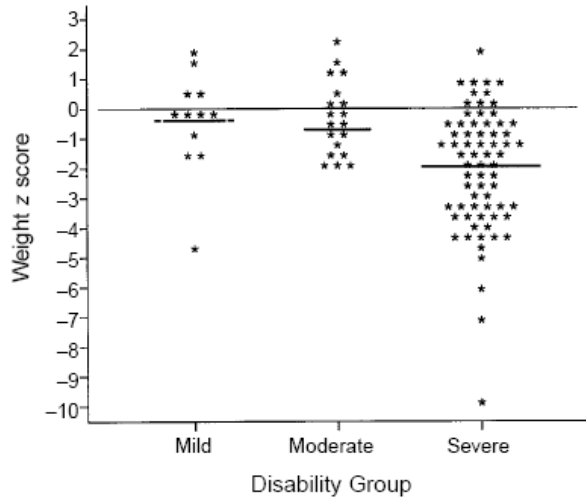


*Sullivan et al. (2000) Developmental Medicine and Child Neurology*

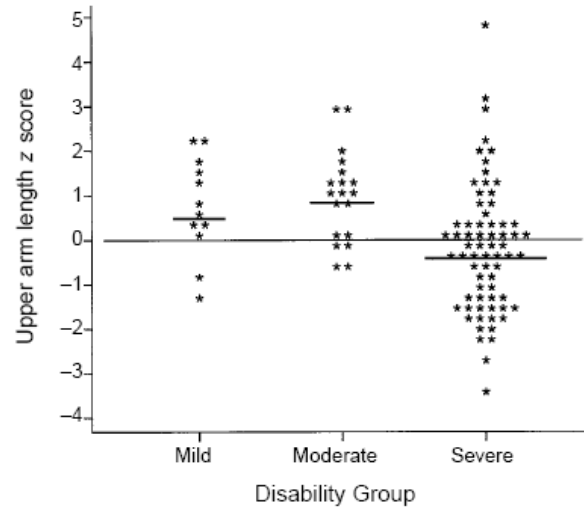
## THE OXFORD FEEDING STUDY: Results (1)

- 377 children aged 3 - 11years with motor deficit ± feeding problems
- Cerebral palsy 86% (233/271)
  - Unable to walk 47% (126/267)
  - Speech difficulty 78% (212/271)
  - Continuous drooling 28% (76/270)

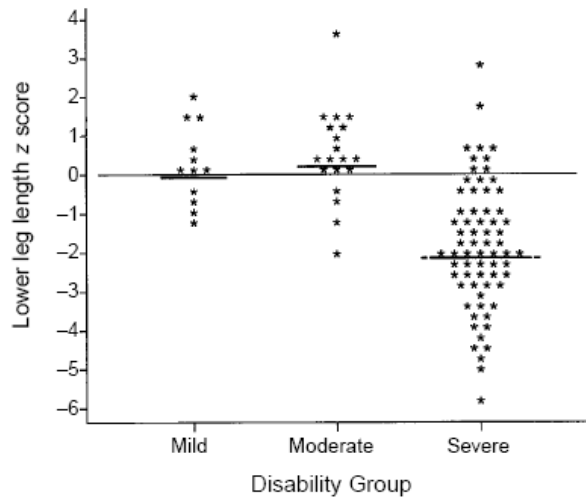
<i>Feeding/nutritional problem</i>	<i>Number</i>	<i>%</i>	<i>Severity of motor impairment</i>		
			<i>Mild</i>	<i>Moderate</i>	<i>Severe</i>
Help with feeding needed	238/268	89	27	85	126
Choking with food	142/257	56	12	38	90
Feeding reported as stressful or not enjoyable by parent	51/262	20	5	11	35
Prolonged ( $\geq 3$ hrs/d) feeding times	71/258	28	3	8	60
Parents considered child underweight	93/240	38	6	25	62
Child received calorie supplements	23/271	8	1	2	20
Gastrostomy feeding	20/265	8	1	0	19
Never had feeding nutritional status assessed	169/264	64	32	77	60
Frequent vomiting	55/249	22	1	12	42
Bowels opened > every 3 days	68/267	26	5	16	47



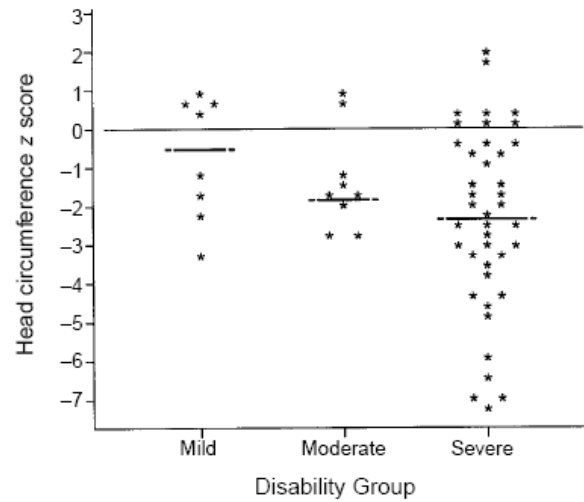
**Figure 2:** Dotplot of bodyweight z score by disability group. Line indicates median value for each disability group.



**Figure 4:** Dotplot of upper arm length z score by disability group. Line indicates median value for each disability group.



**Figure 3:** Dotplot of lower leg length z score by disability group. Line indicates median value for each disability group.



**Figure 5:** Dotplot of head circumference z score by disability group. Line indicates median value for each disability group.

## **THE OXFORD FEEDING STUDY: Summary**

- First epidemiological study of the feeding, gastrointestinal and nutritional problems encountered in disabled children
- Feeding problems in children with neurological impairment are common, severe and cause parents much concern

# Assessment of Feeding and Nutrition in the disabled child

Assessment encompasses:

- **History**
  - Medical
  - Feeding
  - Dietetic
- **Examination**
  - Physical
  - Anthropometric
  - Dietetic
- **Investigation**
  - Videofluoroscopy
  - Lower oesophageal pH monitoring

# Respiratory illness in cerebral palsy

- Malnutrition
- Inefficient respiratory muscles
- Inadequate cough
- Immobility
- Chest wall deformity
- Aspiration

# Assessment of Feeding and Nutrition in the disabled child

- Assessment of growth
  - anthropometry
- Assessment of nutrition
  - dietary diary
  - bioelectrical impedance
  - doubly-labelled water (TBW)

# Assessment of Feeding and Nutrition in the disabled child

## Oral-motor assessment

- Is feeding achieving adequate nutrition?
- Is feeding safe?
- Is feeding efficient, comfortable and enjoyable?

*(After Couriel)*

# Assessment of Feeding and Nutrition in the disabled child

- Video-fluoroscopic studies
  - Oral-motor function
    - Poor lingual function
    - Delayed swallow reflex
    - Poor pharyngeal peristalsis
  - Swallow safety
    - aspiration
    - penetration

# Nutritional Management

## More Effective Feeding

- Oral-motor therapy
- Adaptive seating/utensils
- Naso-gastric tube
- Gastrostomy
- Jejunostomy
- Continuous pump assisted /bolus feeds

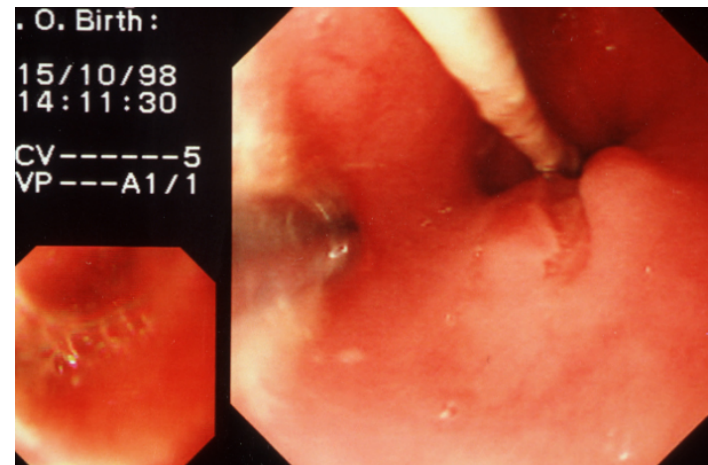
# Nutritional Management

- Dietary supplements:
  - ↑ calorie density
    - Glucose polymers
    - Long-chain triglycerides
  - Micronutrients
  - Fibre

# Naso-gastric tube feeding

Not a long-term solution

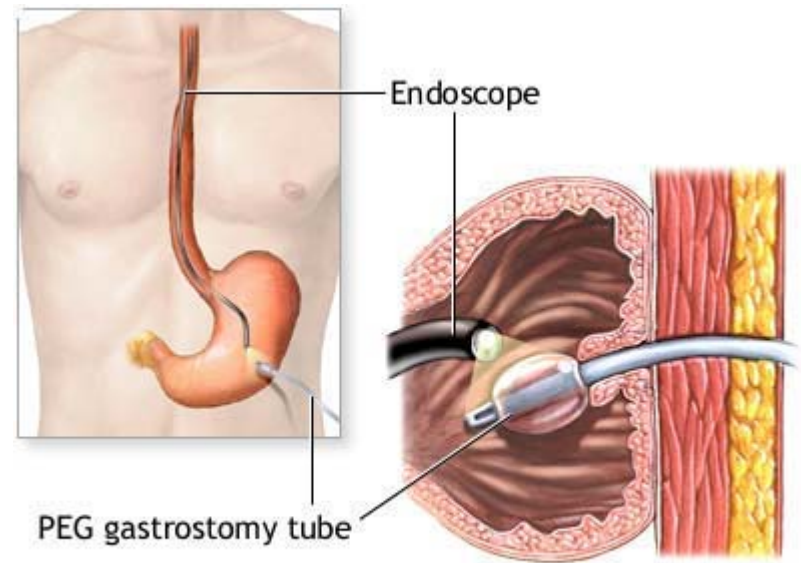
- Uncomfortable
- Unaesthetic
- Frequent dislodgment
- Oesophageal erosion
  - anaemia



# Gastrostomy Tube Feeding

## Indications:

- Unsafe swallow
- Malnutrition 2<sup>o</sup> to Oral-motor Dysfunction
- NGT dependency



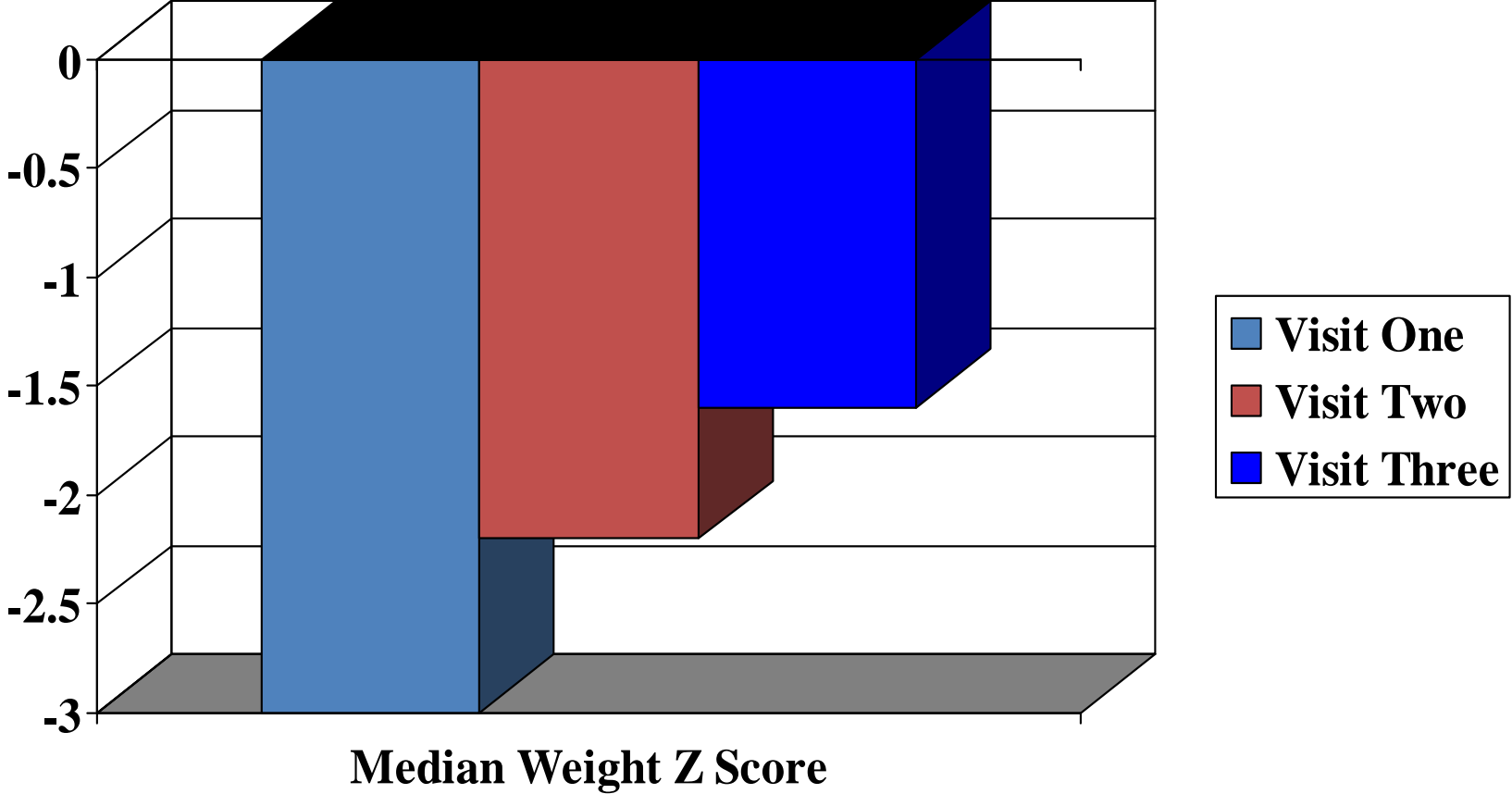
© ADAM, Inc.

Sullivan et al (2005) **Gastrostomy tube feeding in children with cerebral palsy: a prospective, longitudinal study.** *Developmental Medicine and Child Neurology* 47:77-85

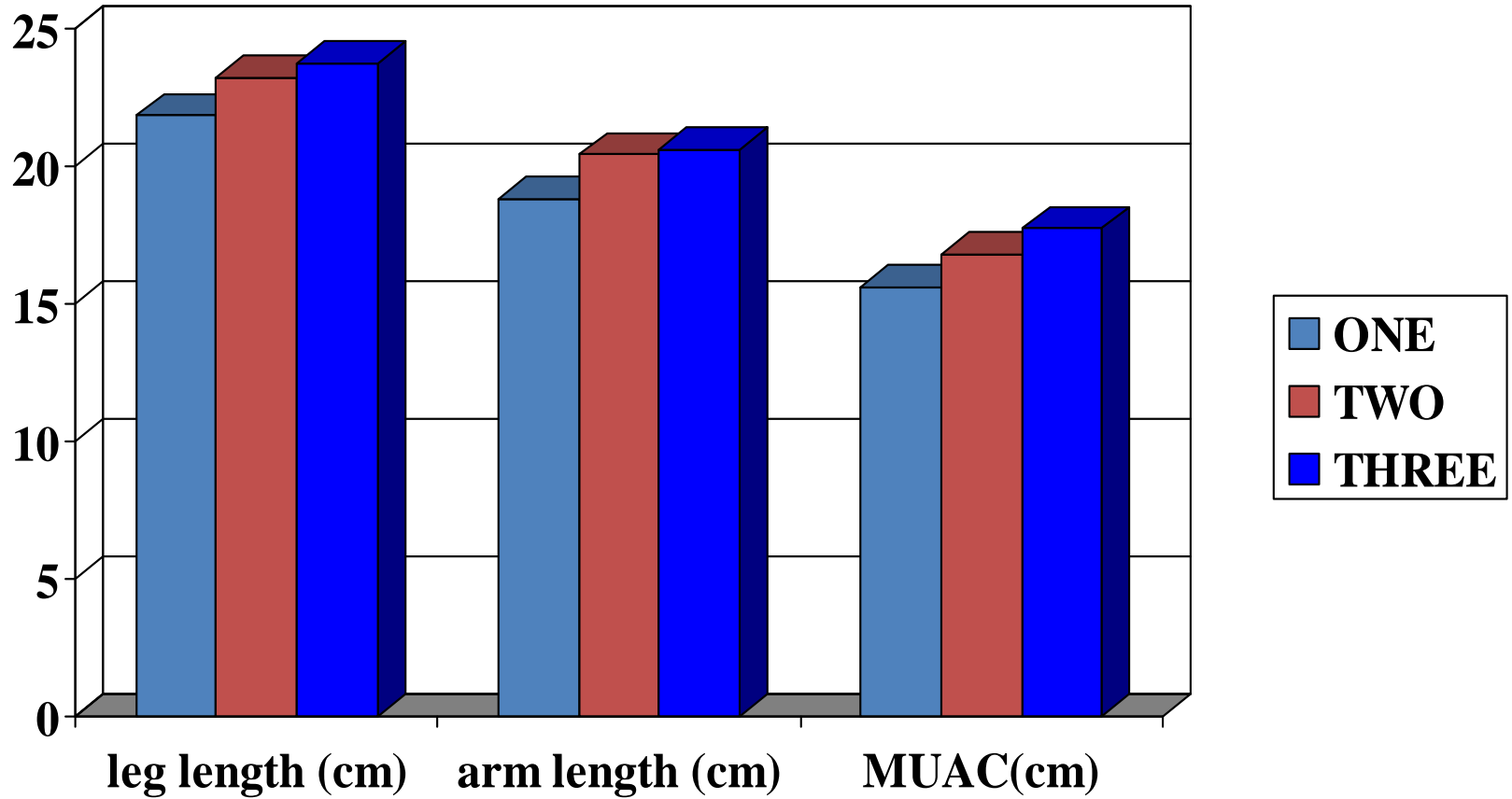
- Effect of gastrostomy tube feeding on:
  - Growth
  - Nutritional Status
  - Care-taker Quality of Life



# Growth



# Growth II



# Results – Feeding time

- Pre G tube: 29/53 (54% ) carers reported feeding time > 2 hours/d
- 6 mo post G tube: 38/53 (71%) reported significantly shorter feeding time
  - 33/53 (62%) < 1 hour per day

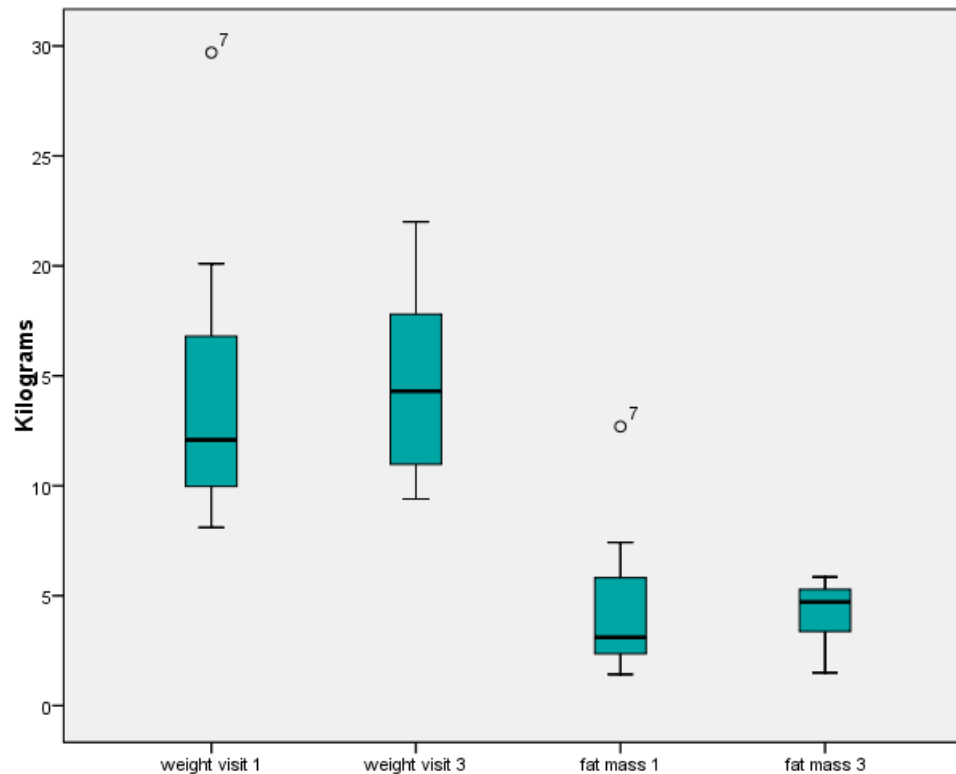
# Results –carers perceptions

- 75% carers concerned about child's nutrition pre-G tube
  - 6 mo post G tube 61% thought child “right size”
  - 12 mo post G tube 67% thought child “right size”
    - 17% thought child “too big”

	Gastrostomy		Oral		p <sup>1</sup> (only those with follow up data)
	n	Median (range)	n	Median (range)	
Age, y	22	9.0 (1.3 to 14.6)	18	8.0 (1.3 to 18.9)	0.76 (0.73)
Weight, kg	22	19.6 (8.9 to 35.8)	18	15.9 (9.0 to 65.2)	0.57 (0.36)
Weight, z score	22	-2.8 (-6.5 to 2.7)	18	-3.2 (-7.0 to 3.0)	0.11 (0.10)
Triceps skin fold thickness, z score	22	-0.6 (-1.5 to 2.0)	18	-1.3 (-2.1 to 1.8)	0.01 (0.01)
Fat free mass index (kg/m <sup>2</sup> )	17	9.8 (7.8 to 12.7)	14	10.9 (9.1 to 15.9)	0.08 (0.03)
Fat mass index (kg/m <sup>2</sup> )	17	4.1 (0.1 to 8.3)	14	2.9 (0.4 to 17.9)	0.02 (0.03)
Resting metabolic rate per kg body weight (kcal/24 hours per kg)	19	35.4 (25.1 to 59.5)	16	41.8 (22.2 to 60.9)	0.25 (0.56)
Total energy expenditure per kg body weight (kcal/24 hours per kg)	21	43.7 (20.9 to 94.1)	17	62.8 (22.7 to 93.6)	0.04 (0.14)

	N	Visit 1 median (IQ range)	Visit 3 median (IQ range)	Wilcoxon p value N=6
<b>Weight (kg)</b>	14	12.09 (7.04)	14.3 (7.06)	0.012
<b>Fat mass DLW (kg)</b>	11	3.11 (4.67)	4.71 (2.53)	0.347
<b>Fat % DLW</b>	11	28.27 (26.69)	31.85 (13.84)	0.173

**Mass and fat mass change between visits 1 and 3**



# Quality of Life Scores

Category	Visit 1	Visit 2 (6 m)	Visit 3 (12 m)	OHLS control	Visit 1 v OHLS p value	Visit 2 v OHLS p value	Visit 3 v OHLS p value
<b>Physical Functioning</b>	82.78	84.67	84.26	88.4	0.068	0.3	0.2
<b>Role Physical</b>	73.26	73.96	81.5	85.82	0.004	0.03	0.3
<b>Role Emotional</b>	68.22	73.56	80.25	82.93	0.002	0.07	0.5
<b>Social Functioning</b>	65.91	63.75	76.85	88.01	<0.0001	0.004	0.02
<b>Mental Health</b>	62.78	67.03	70.37	73.77	0.0001	0.03	0.3
<b>Energy/ Vitality</b>	45.69	49.22	57.64	61.13	<0.0001	0.008	0.3
<b>Pain</b>	76.94	77.82	75.46	81.49	0.2	0.4	0.2
<b>General Health</b>	65.14	65.42	75.96	73.52	0.009	0.048	0.4

When compared with OHLS mean values:

- significantly lower mean scores
- Improvement after 6 months but still significantly lower
- No significant improvement after 12 months

# Cerebral Palsy: Nutritional Management

- Gastrostomy is not a panacea for nutritional disorders and growth retardation in children with cerebral palsy
- May not improve nutritional status
- Does facilitate patient care

# Cerebral Palsy: Nutritional Management

## Gastrostomy: Work-Up

- Careful pre-op evaluation (GOR)
- Improve nutritional status (TPN)
- Improve pulmonary function (PT)

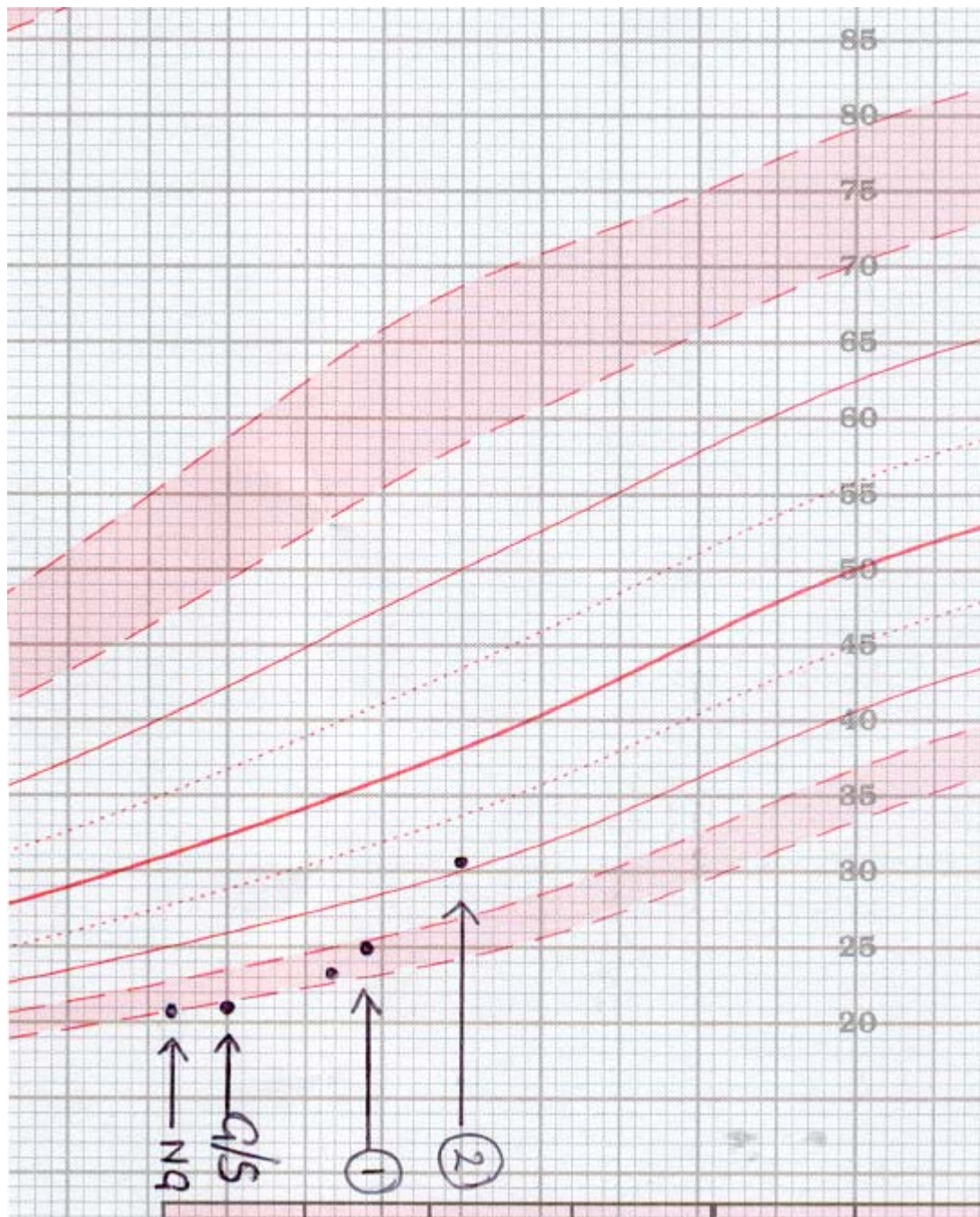
# Nutrition and the disabled child

## Gastrostomy-tube complications

- Surgical procedure
- Peritonitis
- Overfeeding
- Skin excoriation/granulation
- Gastro-oesophageal reflux

## Gastrostomy: Follow-Up

- Growth
- Vomiting/hematemesis
- pH monitoring
- ? Continuous pump feeding



# Outcomes

Enteral feeding leads to increase in:

- Weight
- Weight-for-Height
- Muscle and fat
- Peripheral circulation
- Immune function
- Cognitive ability
- General well-being

# Feeding Clinics

## Multi-disciplinary team approach

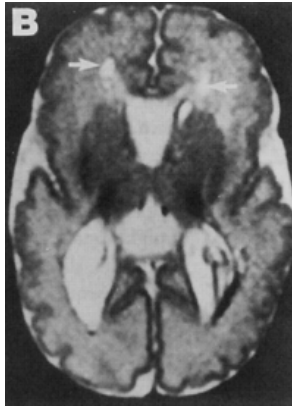
- Core team
  - Paediatric gastroenterologist
  - Paediatric Dietitian
  - Clinical Nurse Specialist
  - Speech and Language Therapist
  
- Extended clinical team
  - Paediatric surgeon
  - Radiologist
  - Paediatric neurologist
  - Community Paediatrician

# Consensus research priorities for cerebral palsy: a Delphi survey

*DMCN March, 2010*

Research question	Rank (mean)
How can CP be prevented?	1 (5.98)
What are the optimal treatments for CP?	2 (5.95)
<b>What potential does the brain have to repair injury?</b>	<b>3 (5.85)</b>
Can stem cells have a therapeutic effect for CP?	3 (5.85)
What are the long term outcomes of treatments?	3 (5.85)
What factors have the greatest impact on improving the lifestyle and QoL of individuals with CP?	6 (5.83)
What are the causes and causal pathways to CP?	7 (5.80)
What policies are needed to improve QoL for families caring for (Australians) with severe disabilities?	8 (5.78)
What is the optimal intensity of therapy programmes?	9 (5.75)
What are the most effective methods of educating parents to help improve their child's independence and function?	9 (5.75)

## Perinatal Brain Damage



## RISK FACTORS:

Maternal chorioamnionitis

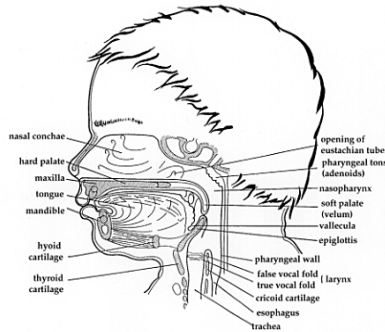
Extreme prematurity

H.I.E./cPVL

Term Asphyxia

Poor suck/feed

THE MOUTH AND PHARYNX OF THE NEWBORN  
(sagittal section)



Malnutrition/Cerebral palsy



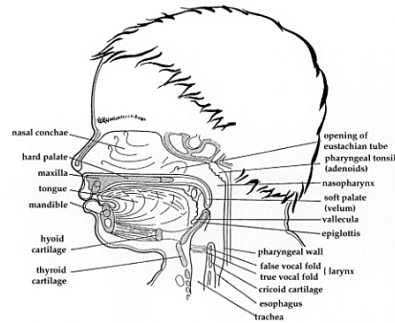
## Diagnosis of CP:

Clinically > 6 months



**Brain plasticity:  
regeneration and repair  
(human and animal  
studies)**

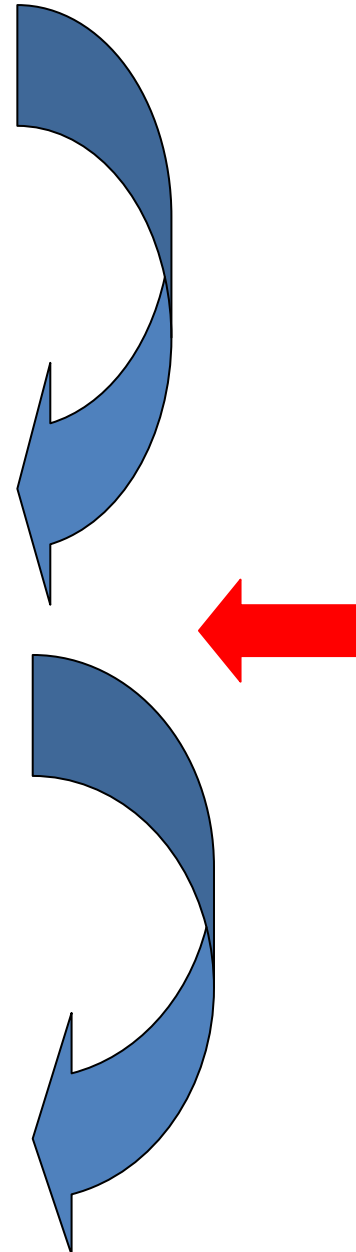
**THE MOUTH AND PHARYNX OF THE NEWBORN  
(sagittal section)**



**Better suck/feed**

**NUTRITIONAL  
INTERVENTION:  
Quantity & Quality**

**No malnutrition  
? Amelioration of  
cerebral palsy**



# Feeding and Nutrition in Children with Neurodevelopmental Disabilities

*edited by Peter B. Sullivan*



A practical guide from Mac Keith Press