# Nutrition Management for Children with Developmental Disabilities

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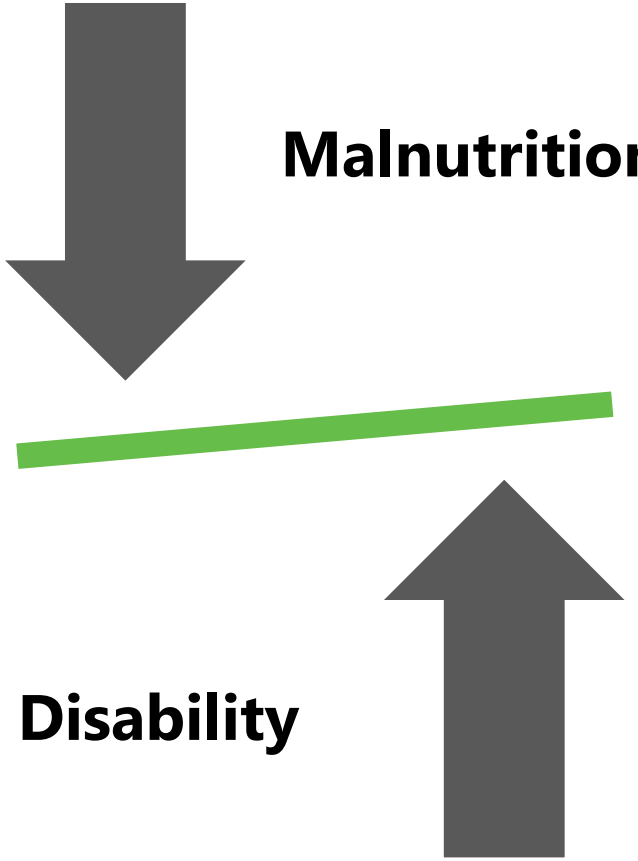
Nutrition and Disability are intimately linked. Malnutrition can directly cause or contribute to disability and disability can lead to malnutrition.

Risk factors leading to malnutrition and disability are multi-faceted and encompass biological, physical, environmental and social factors.

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- Assessing and treating nutrition issues for children with developmental disabilities should not be just left to the specialist.
- All disciplines bear some responsibility to recognize signs of growth failure and malnutrition.
- A multi-disciplinary team can provide a safety net to ensure the early and frequent evaluation of nutrition concerns.

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# OBJECTIVES

- Recognize nutrition risk factors in children with disability
- Identify the nutrients of concern in this population
- Evaluate the strategies used to assess growth
- Discuss intervention options that are easily done in the home

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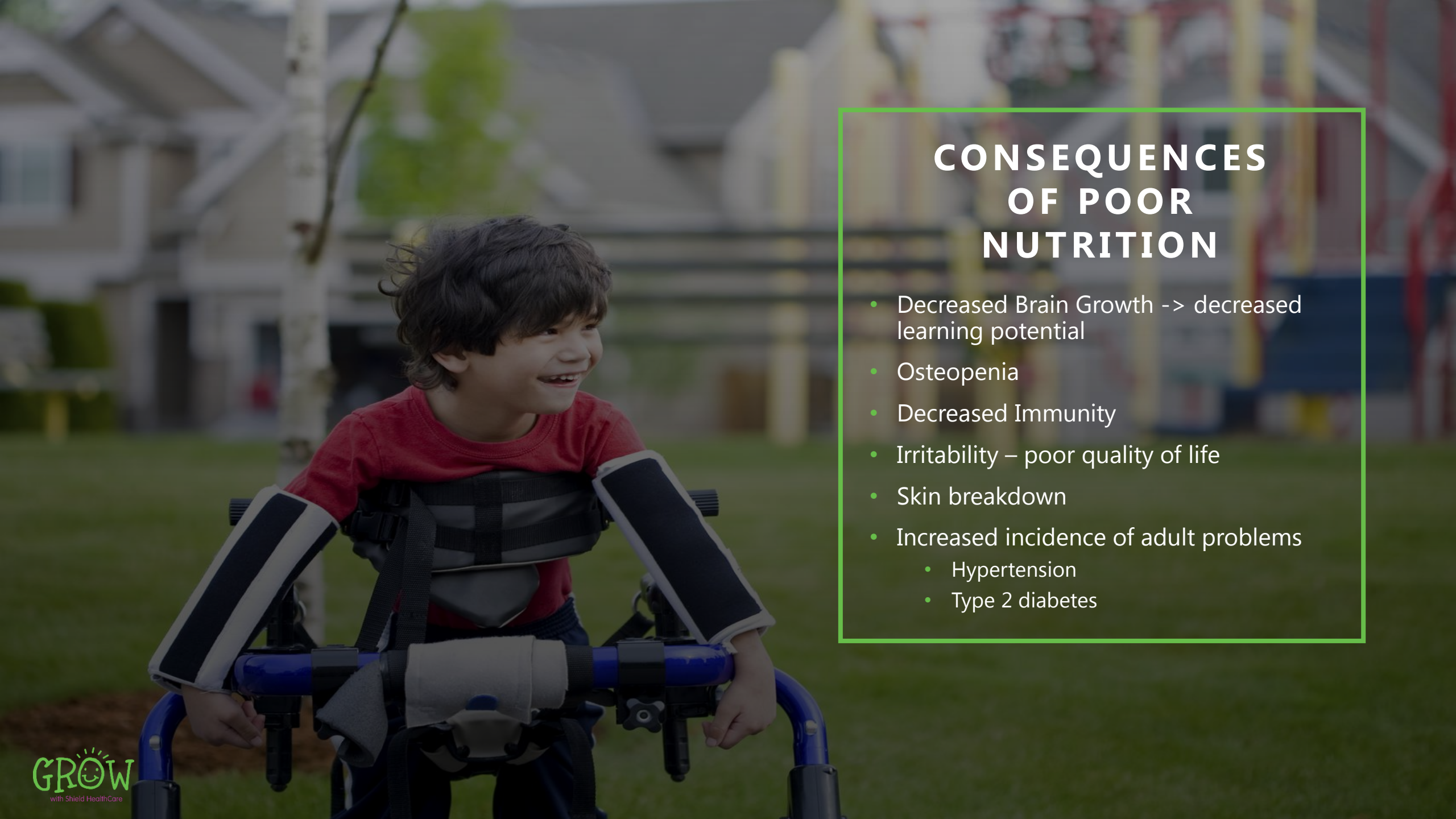

# CONSEQUENCES OF POOR NUTRITION

- Decreased Brain Growth -> decreased learning potential
- Osteopenia
- Decreased Immunity
- Irritability – poor quality of life
- Skin breakdown
- Increased incidence of adult problems
  - Hypertension
  - Type 2 diabetes

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# SOCIAL COST

- Increased healthcare costs throughout the lifetime
- Loss of developmental potential
- Increased morbidity and mortality
- Alterations in family structure

# WHO'S AT RISK?

**Cerebral Palsy**
- Perinatal Brain Injury

**Neuromuscular Disease**
- Muscular Dystrophy
- Motor-Neuron disease

**Degenerative Disease**
- Rett Syndrome
- Adrenal Leukodystrophy

**Mitochondrial disorders**
- Leigh's Disease

**Genetic Dysmorphisms**
- Down Syndrome
- Trisomy

**Anatomic**
- Cleft Lip and Palate
- Pierre Robin Sequence

**Trauma**
- MVA
- Near Drowning

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# CAUSES OF POOR NUTRITION IN DISABILITY

| Medical | Educational | Social/Economic |
|---|---|---|
| • Anatomic<br>- Cleft Lip & Palate<br>- Pierre Robin | • Knowledge Deficit<br>- Positioning<br>- Nutritional Needs | • Decreased breastfeeding<br>- Underfeeding<br>- Increased cost of nutrition |
| • Mechanical<br>- Cerebral Palsy<br>- Spina Bifida | • Improper feeding technique<br>- Texture<br>- Equipment | • Parental stress<br>- Difficult/ prolonged feeding times |
| • Syndrome<br>- Down Syndrome<br>- Trisomy | • Lack of Therapy | • Economic Burden<br>- Loss of income due to caregiving |

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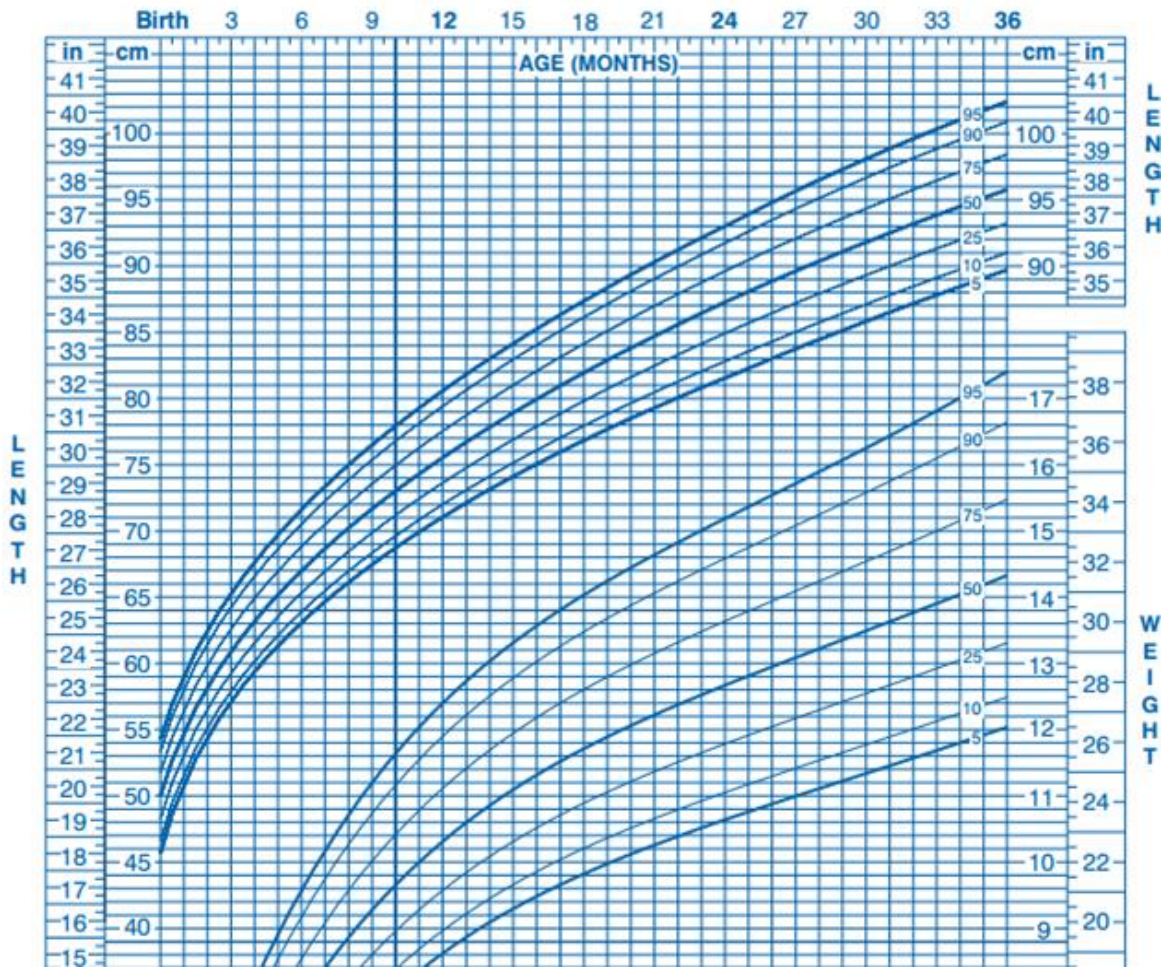
# FAILURE TO THRIVE

- Decelerated or arrested physical growth – associated with abnormal growth and development
- Height and weight measurements fall below the third or fifth percentile, or a downward change in growth across two major growth percentiles.

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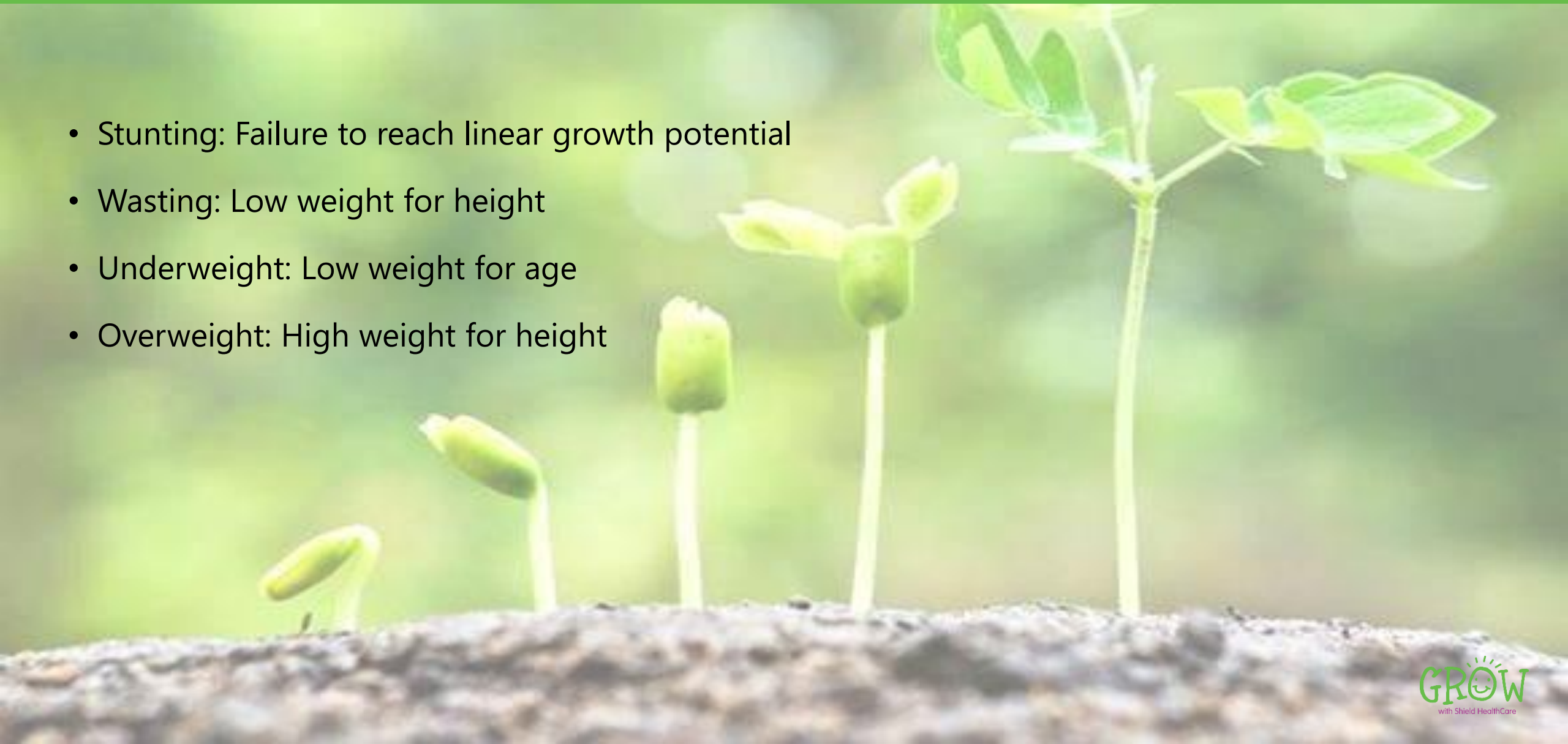
# GROWTH AND POOR NUTRITION



- Stunting: Failure to reach linear growth potential
- Wasting: Low weight for height
- Underweight: Low weight for age
- Overweight: High weight for height

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# MACRONUTRIENTS - CALORIES

Energy intake is always primary to evaluation and treatment

- How much?
  - How fast?
- Current nutrition state
- Catch up growth needs
- May be condition specific

Energy intake underlies all other nutrient requirements

- Value of carbohydrate and fat

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# ENERGY REQUIREMENTS

| CLINICAL CONDITION | CALORIE REQUIREMENTS |
|---|---|
| Cerebral Palsy<br><br>Athetoid Cerebral Palsy | 13.9 kcal/cm height with mild to moderate activity<br>11.1 kcal/cm with severe physical restrictions<br><br>Can be up to 6000 kcal/day in adolescence |
| Down Syndrome<br>• Boys (age 5 – 12 years)<br>• Girls ( age 5 – 12 years) | <br>16.1 kcal/cm height<br>14.3 kcal/cm height |
| Myelomeningocele (Spina Bifida) | 9-11 kcal/cm for maintenance<br>7 kcal/cm for weight loss<br>Approximately 50% RDA for age after infancy |
| Prader Willi | 10-11 kcal/cm for maintenance<br>8.5 kcal/cm for weight loss |

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# MACRONUTRIENTS - PROTEIN

- Should not be counted as a source of calories
- Primary purpose is to synthesize tissue, support immune function especially during periods of illness or stress
- Should be based on **ACTUAL** weight
- Use the RDA (Recommended Dietary Allowance) as a starting point

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# MICRONUTRIENTS - MINERALS

- Calcium
- Phosphorus
- Magnesium
- Zinc
- Iron

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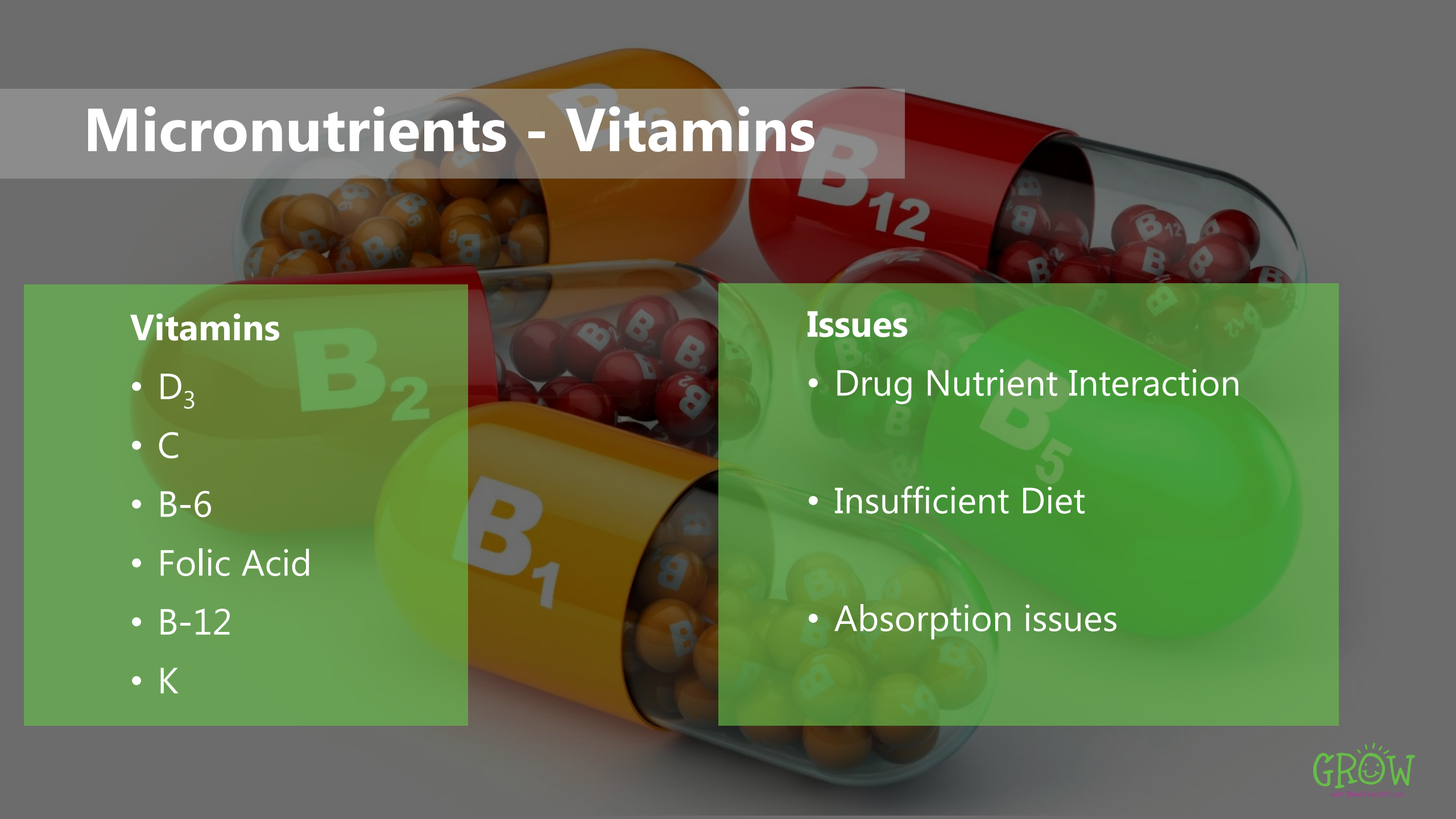
# Micronutrients - Vitamins




**Vitamins**

- $D_3$
- C
- B-6
- Folic Acid
- B-12
- K

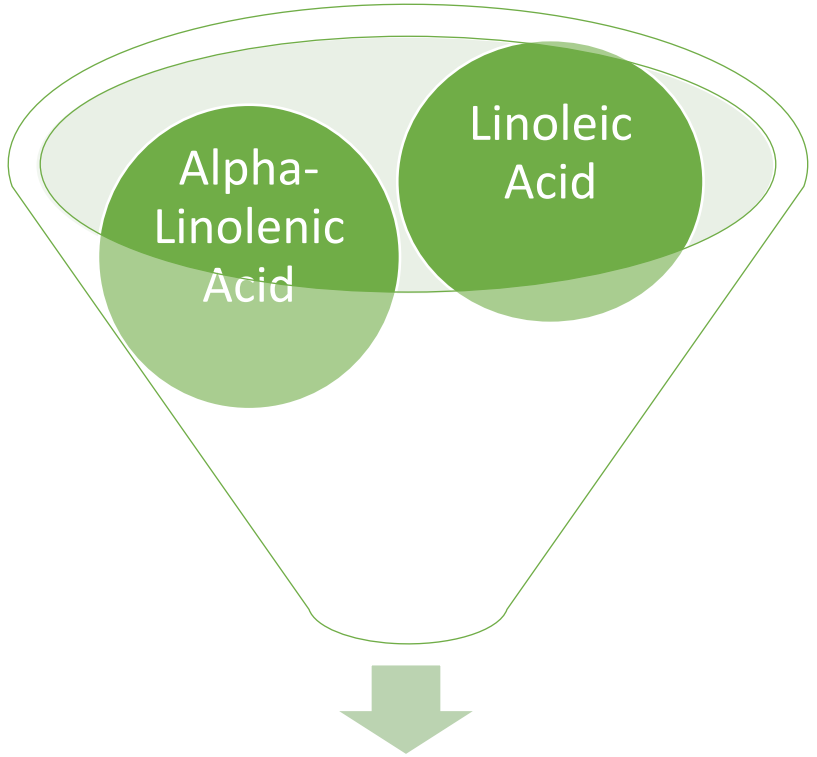
**Issues**

- Drug Nutrient Interaction
- Insufficient Diet
- Absorption issues

# MICRONUTRIENTS
# ESSENTIAL FATTY ACIDS

## DHA

- Important in Brain Growth
- Accrues mainly in the third trimester
- Implicated in visual acuity in infants

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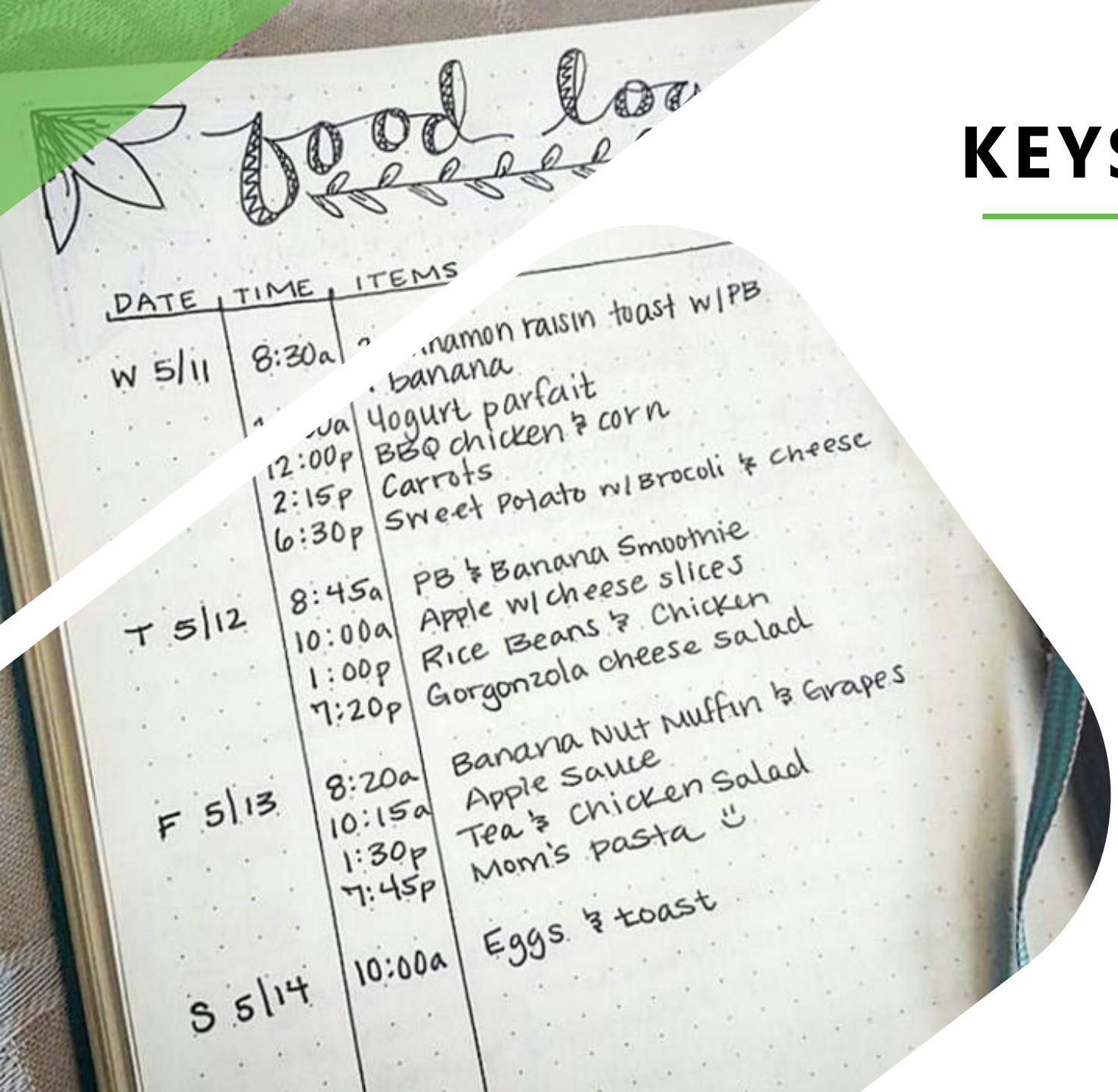


# KEYS TO ASSESSMENT

- Nutritional
  - Eating competence – Ellyn Satter
  - Nutrition history
- Social
  - Food insecurity
  - Knowledge deficit

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# KEYS TO ASSESSMENT

**N**utrition Focused Physical Exam – Pediatric

- Skin
- Eyes
- Hair

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# EVALUATION STRATEGIES - GROWTH

- Importance of accurate anthropometrics
  - Length
  - Length board
  - Weight
  - Fewest clothes possible
  - Head circumference
  - Most useful in children under three

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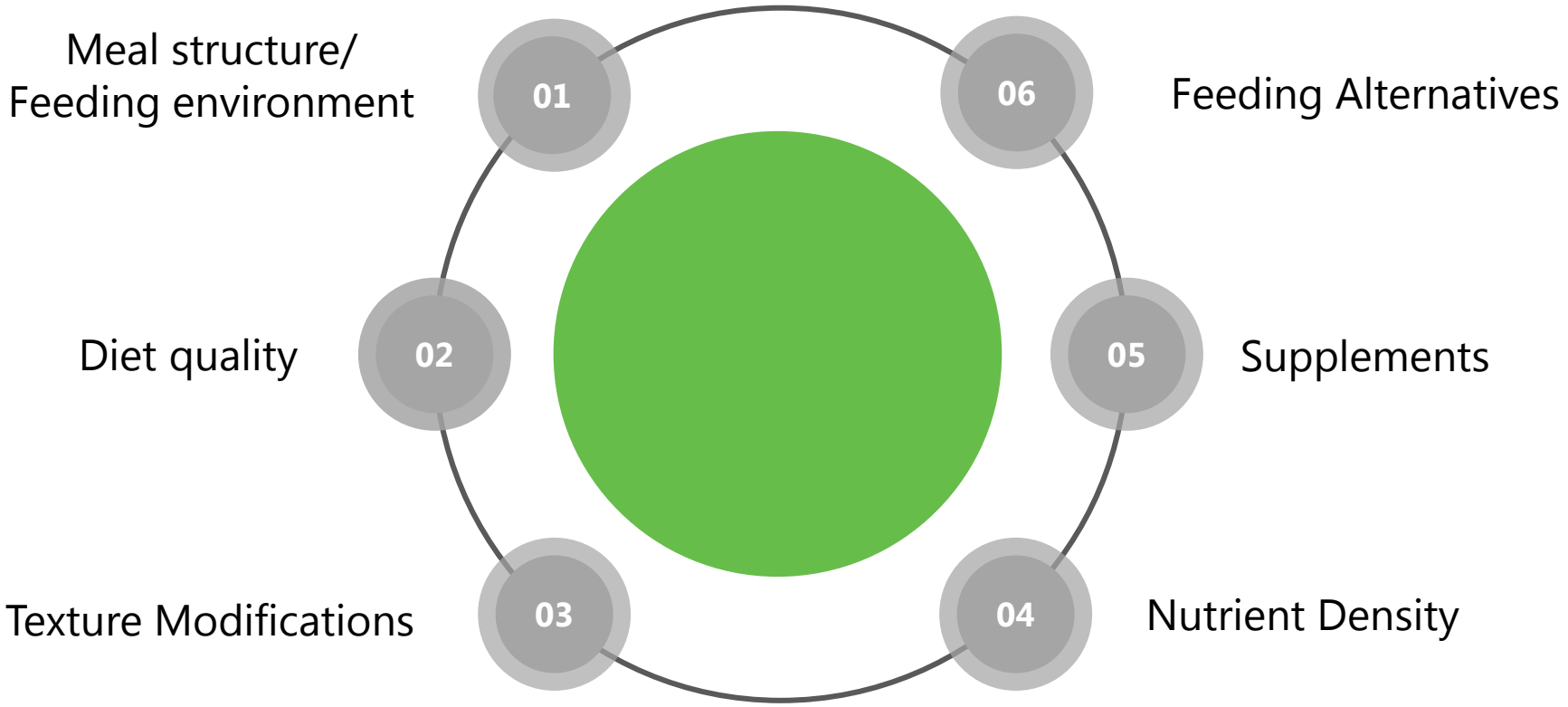
# EVALUATION STRATEGIES - GROWTH

- Tracking growth velocity
  - Specialty growth charts
    - Prematurity
    - Down Syndrome
    - CP
    - Achondroplasia
    - DiGeorge
    - Prader Willi

# Nutrition intervention – Least invasive first

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# Supplements - When to Consider

- Degree of malnutrition
- Time frame to achieve positive nutritional health
- Co-morbidities
  - Wounds
  - Surgeries
  - Illness/Infection
- Outcomes of previous intervention

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# SUPPLEMENTS - WHAT TO ADD

**Modular**

- Carbohydrate modular
- Fat and carbohydrate combination
- Protein, Fat and Carbohydrate modular

**Whole Protein supplements**

- 1 calorie/ml
- Added vitamins and minerals
- Source of energy as carbohydrate

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# Supplements – What to Add

- Peptide based supplements
  - 1 kcal/ml
  - Better tolerated in compromised children
  - Added vitamins and minerals

- High Calorie supplements
  - 1.5 kcal/ml – 2.0 kcal/ml
  - Added vitamins and minerals

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# FEEDING ALTERNATIVES

## Nasogastric tube

- Short term solution
- Move patient back to baseline after illness or surgery
- No long term commitment

## Gastrostomy

- Not necessarily permanent
- Longer term use
- Support energy needs when alternative measures fall short

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QUESTIONS ?
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