Medical and Nutritional Implications of GLP-1 agonist-supported Weight Loss in Down syndrome

- Health Benefits and Nutrition Implications of Weight Loss in Down syndrome
  - Lauren Ptomey, PhD, RD, LD
  - Shannon Frizzell, MS, RD, LDN, CSOWM
  - Dominica Nichols, PhD, RD, LDN

- Medical and Surgical Management of Obesity in Down syndrome
  - Asef Mahmud, MD, FACP, FAAP, DABOM
  - Vibha Singhal, MD, MPH, DABOM
  - Dominica Nichols (moderator)

Health Benefits and Nutrition Implications of Weight Loss in Down syndrome

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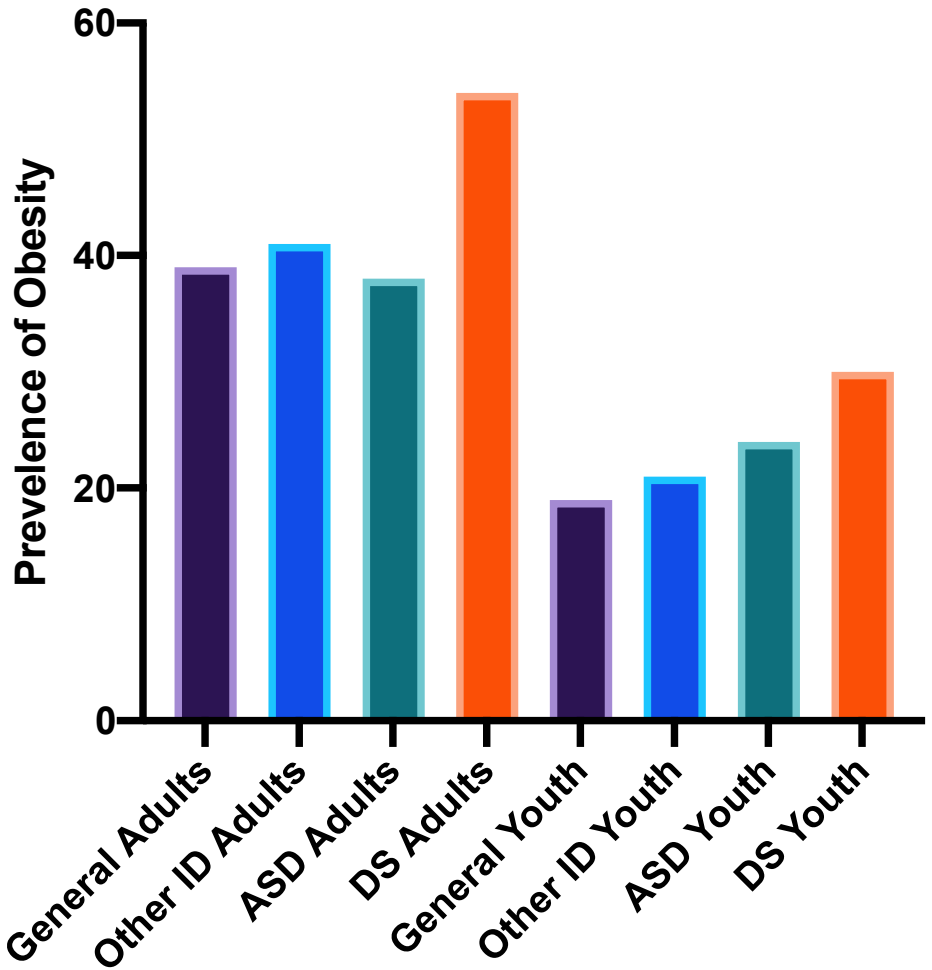
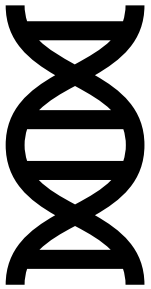
The UNIVERSITY of KANSAS

Prevalence of Obesity in Individuals with Down syndrome



Ptomey/Walpitage. 2020. JIDR

Potential Unique Risk Factors For Poor Dietary Habits In Youth And Adults with Intellectual Disabilities



Genetics

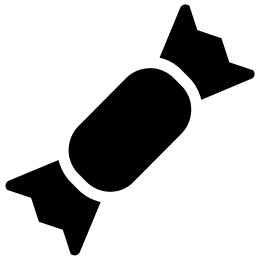
Food Selectivity

Medication

Sleep

Oral motor problems

Behavior Problems

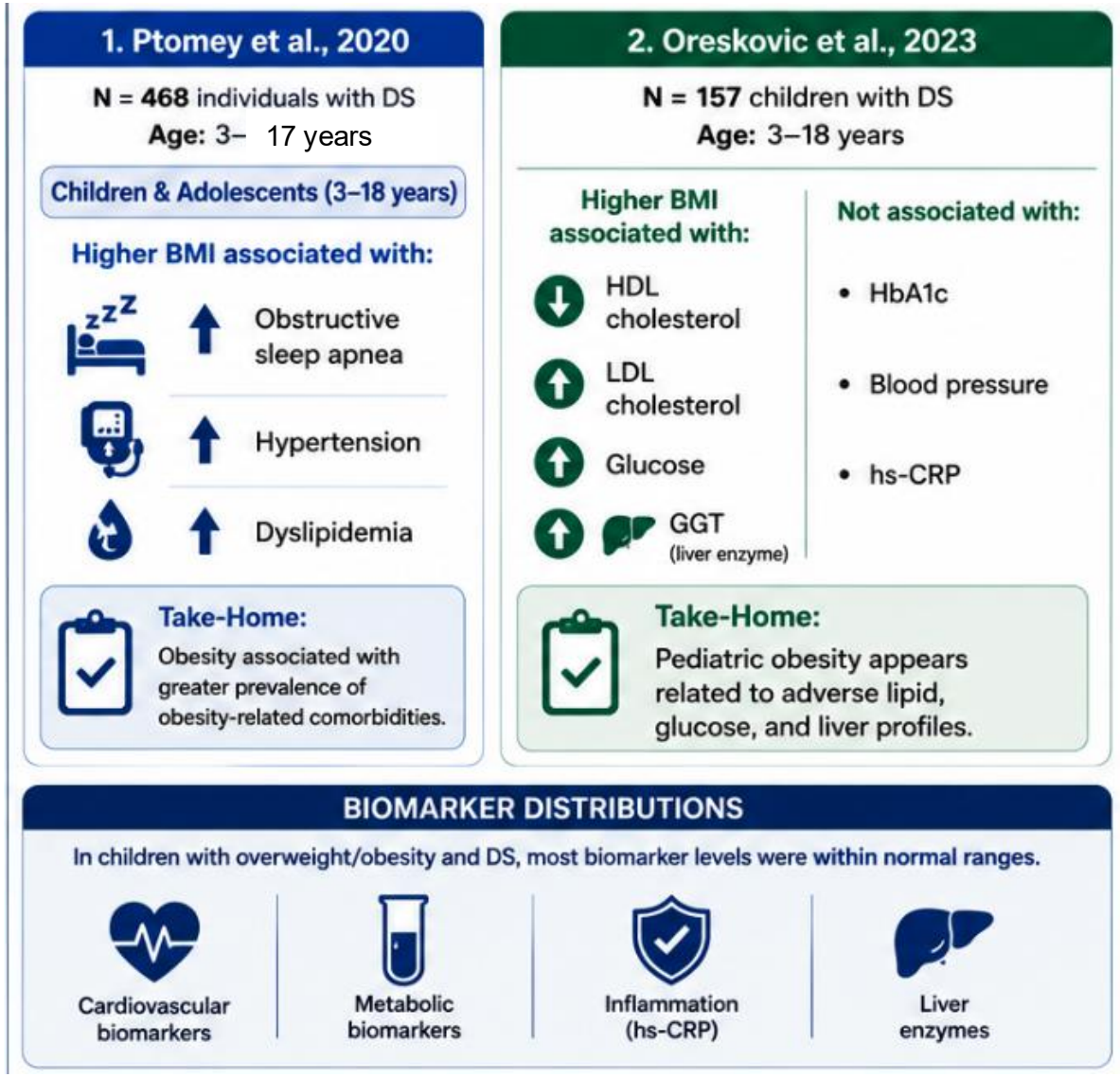


Food as a Reward

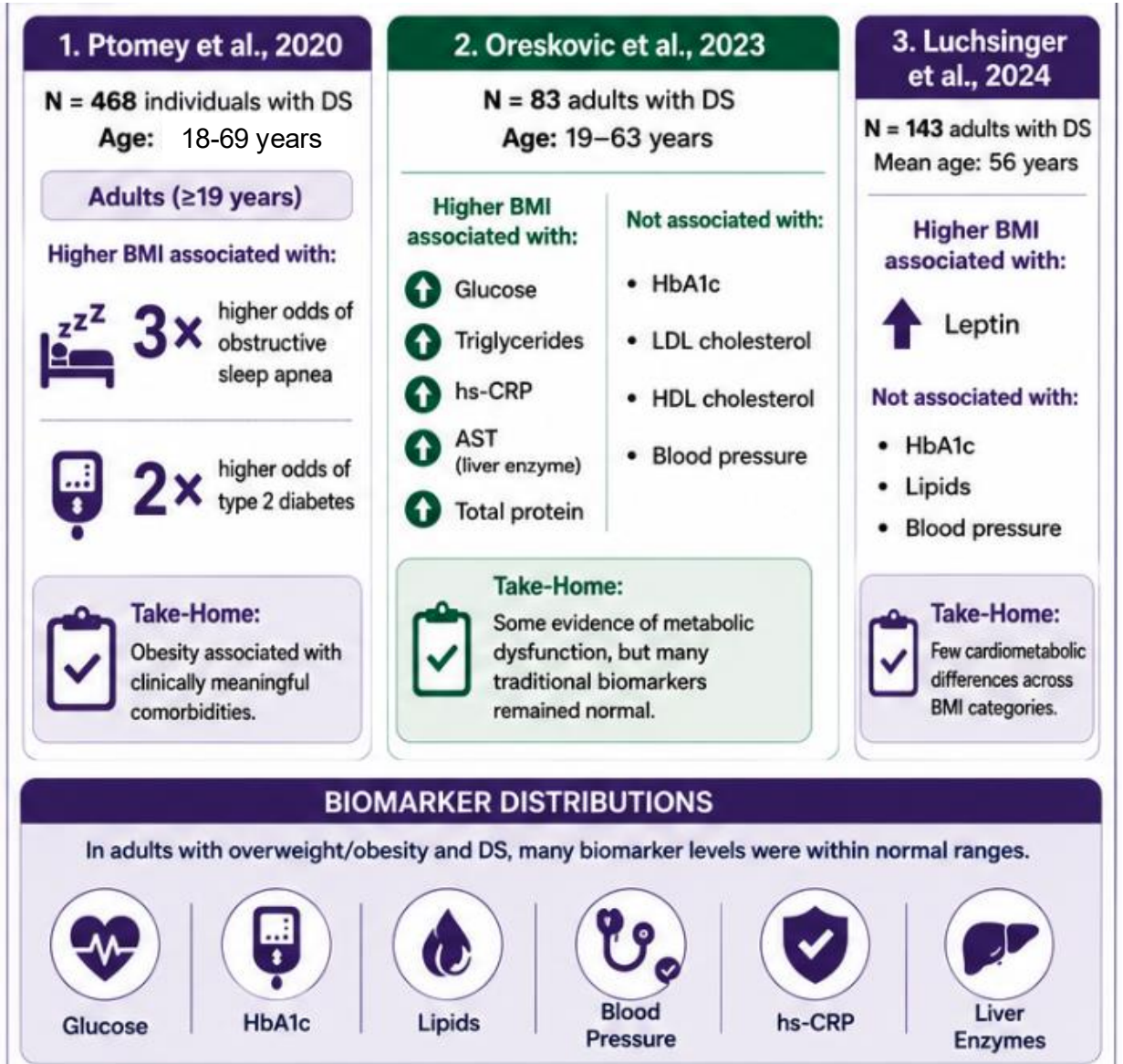
Additional Risk Factors For Obesity in Down syndrome

- Hypotonia
- Increased Leptin
- Decreased Resting Energy Expenditure
- Chronotropic Incompetence

Associations of BMI and Health outcomes in Children and Adolescents with Down syndrome



Associations of BMI and Health outcomes in Adults with Down syndrome

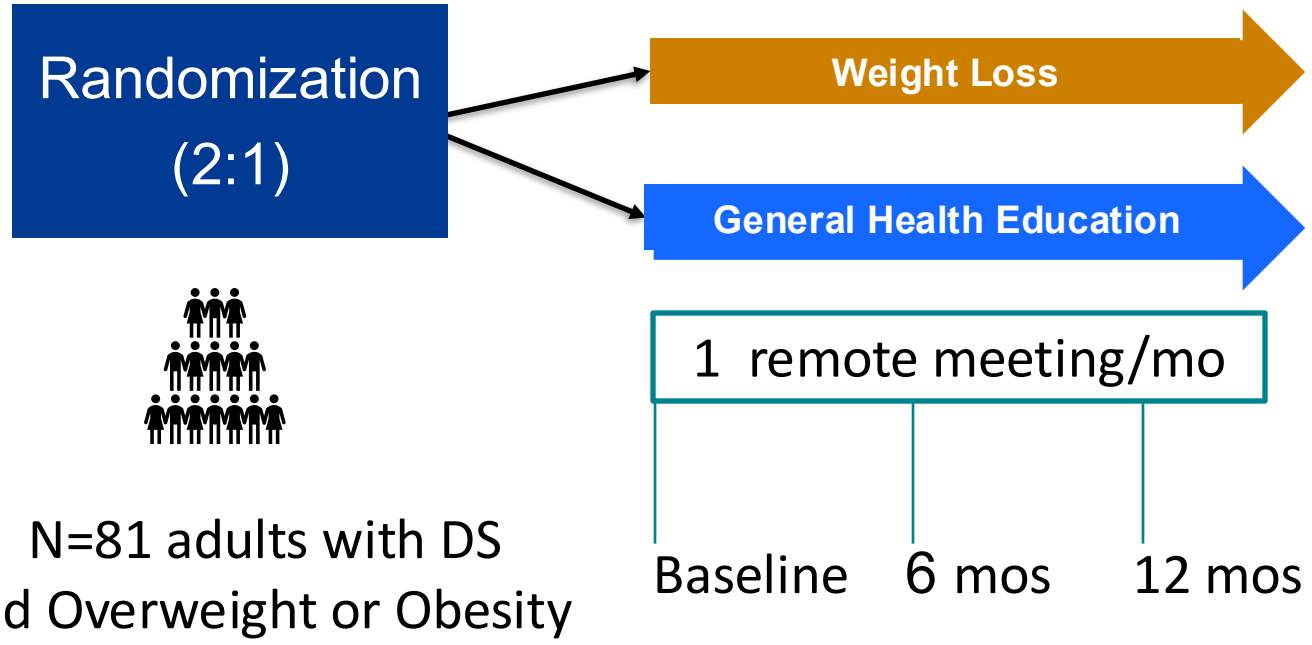


All existing studies are cross-sectional

Only examine BMI and health outcomes

No study has examined whether intentional weight loss impacts health outcomes in adults with Down syndrome

Brain Outcomes with Lifestyle Change in Down Syndrome (BOLD)

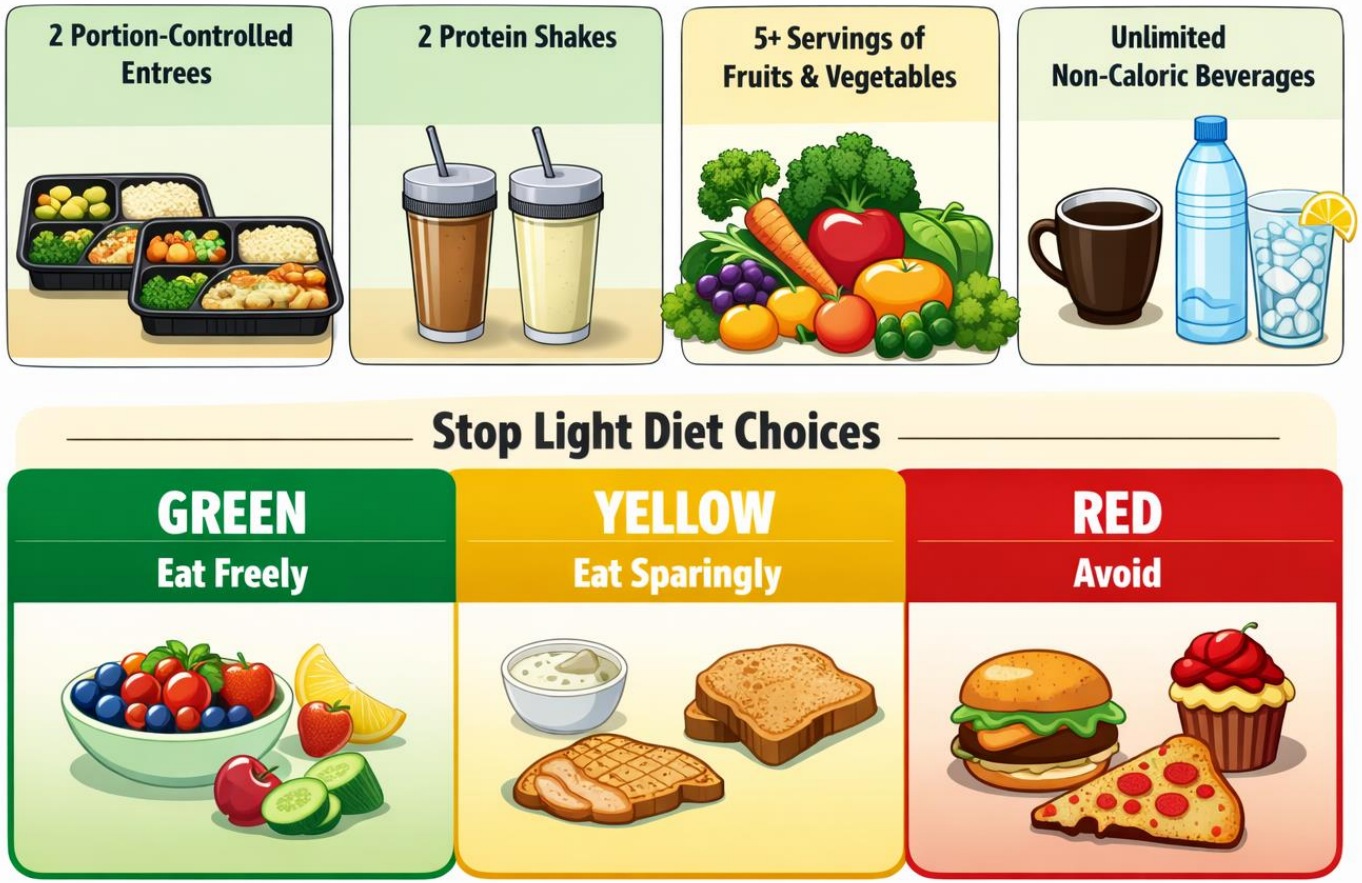


N=81 adults with DS
and Overweight or Obesity

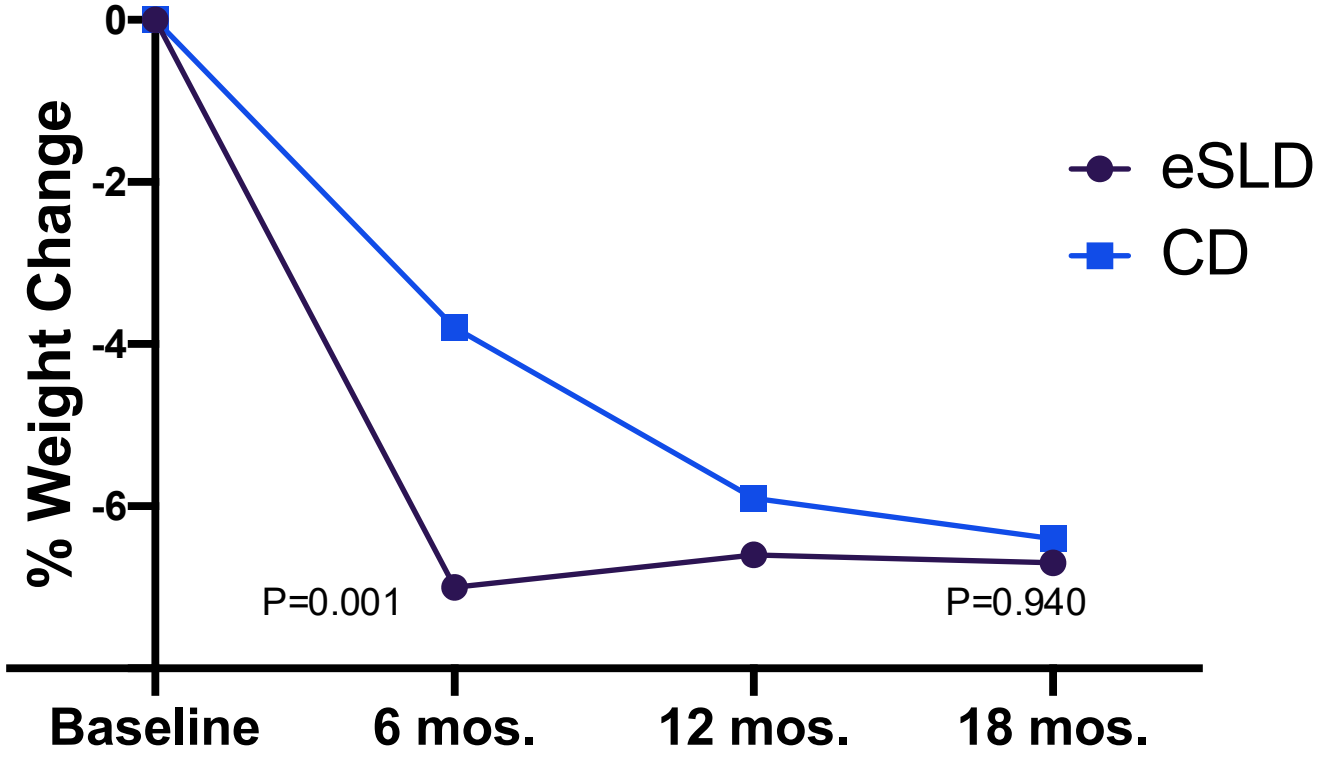
Outcomes

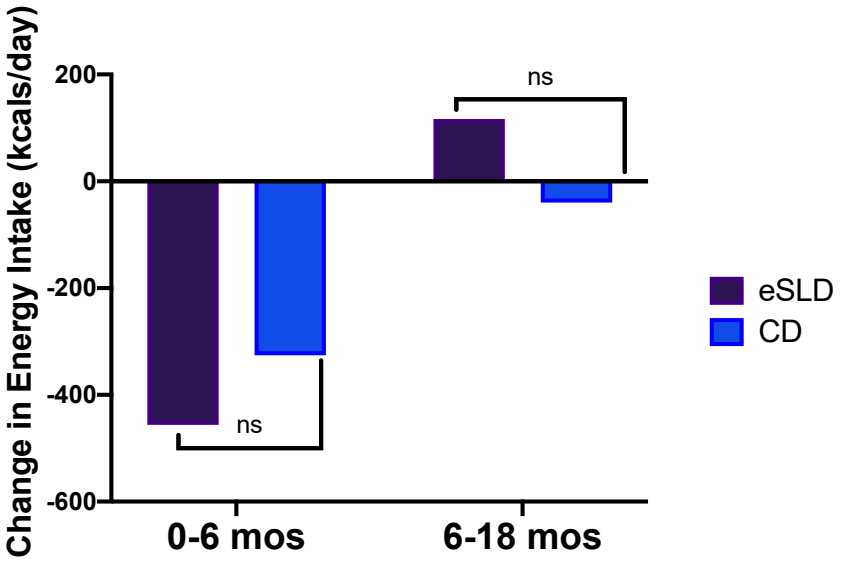
- Weight
- Dietary Intake (food records)
- Physical Activity (wrist worn accelerometer)
- Cognition
  - DSMSE, Cued Recall, Stroop Cats and Dogs, NTG-EDSD, NPI, DLD
- Plasma A/T/N
- MRI/MRS
- HDL,LDL, HbA1c, CBC
- IL-6, CRP, TNF-alpha
- Body composition (Clina F32)

Enhanced Stop Light Diet



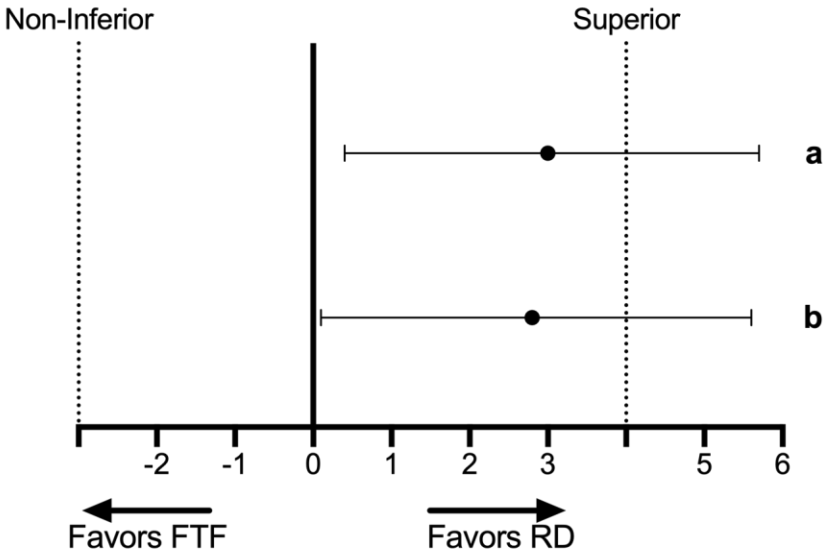
The eSLD Lost Significantly Greater Weight Compared to a Conventional Diet at 6 Months and Maintained for 18 Months in 149 Adults with ID

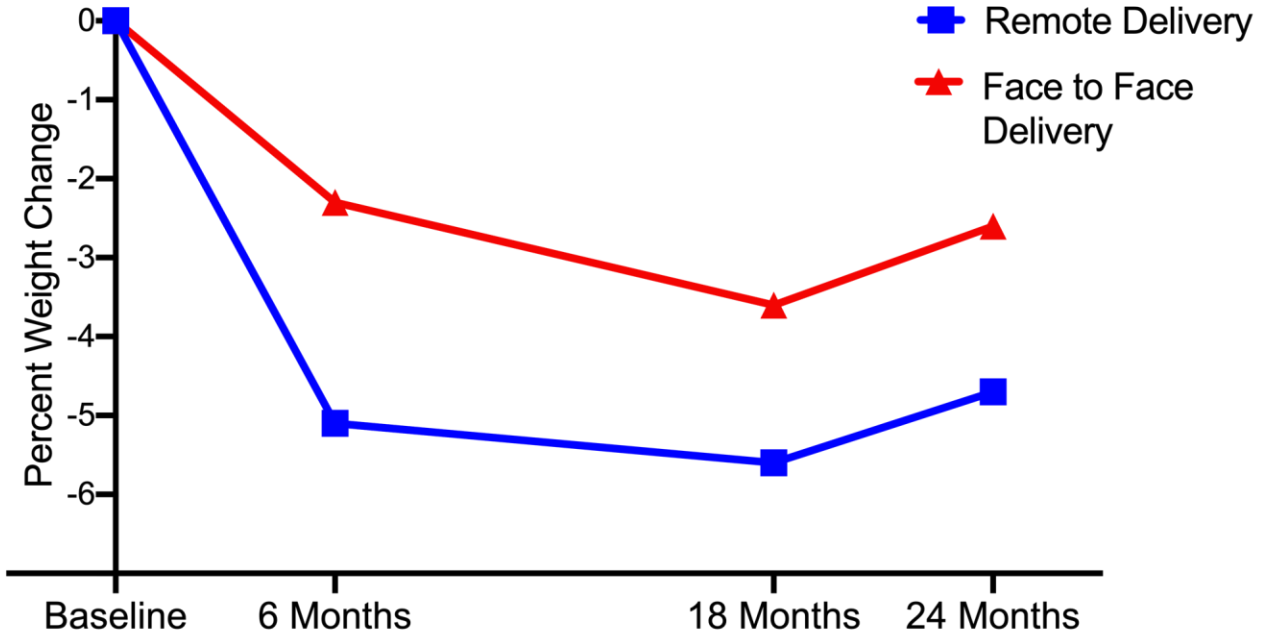




Ptomey et al. 2017

Remote Delivery had Superior Weight Loss in Adults with ID which was Maintained for 24 Months





Ptomey at al. 2024

Baseline Associations of BMI and Body Composition with Health Outcomes in Adults with Down syndrome

BASELINE ASSOCIATIONS

BMI ↑ → **HbA1c ↑** (p = .02)

BMI ↑ → **CRP ↑** (p = .007)

Fat Mass ↑ → **CRP ↑** (p = .002)

Lean Mass ↑ → **HbA1c ↑** (p = .002)

KEY FINDINGS

- Higher BMI was associated with **poorer glycemic control (HbA1c)**.
- Higher BMI was associated with **greater systemic inflammation** (CRP).
- Higher **fat** mass was associated with **elevated inflammation** (CRP).
- Higher lean mass was associated with **higher HbA1c**.

TAKE-HOME MESSAGE

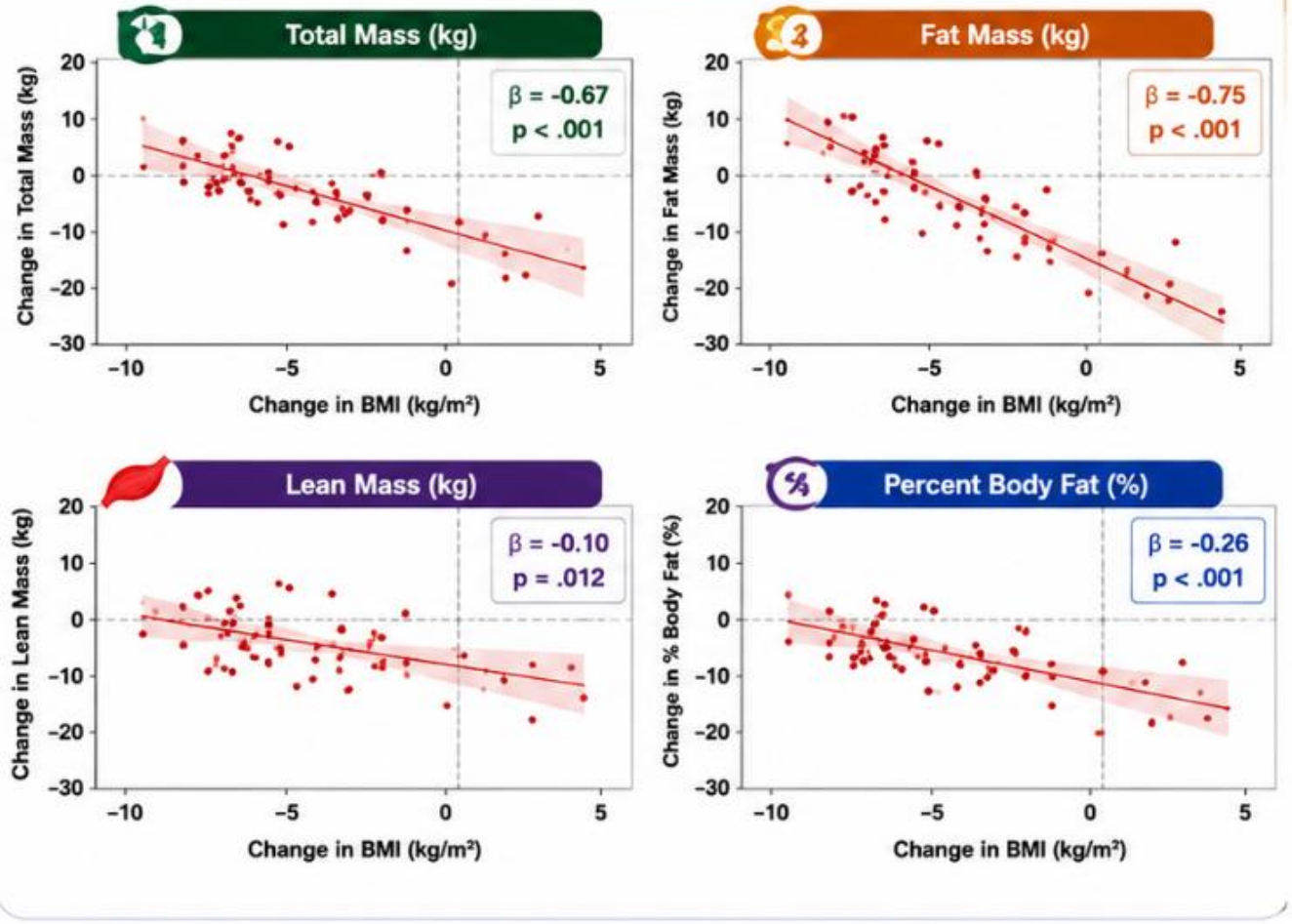
Individuals with greater adiposity demonstrate **worse glycemic control** and **greater inflammation** at baseline.

N = 47 adults
Mean age = 26.9 ± 6.7 years
Mean BMI = 33.2 ± 6.1 kg/m²

All models adjust for age, sex, and diagnosis (DS vs non-DS). ID/DD = intellectual and developmental disabilities; DS = Down syndrome; CRP = C-reactive protein.

Weight Loss Produces Meaningful Improvements in Body Composition

CHANGE IN BMI vs DXA OUTCOMES

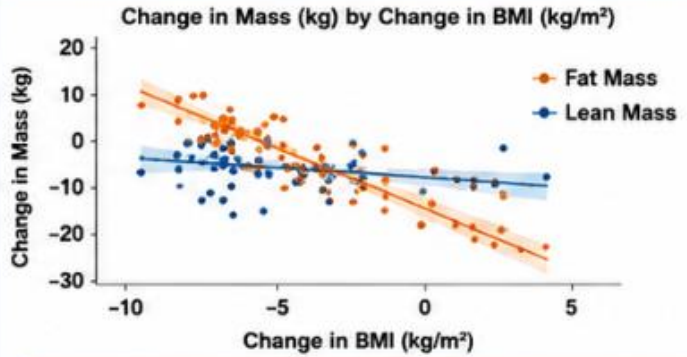


KEY FINDINGS

- Change in BMI is significantly associated with change in **Total Mass.**
- Change in BMI is significantly associated with change in **Fat Mass.**
- Change in BMI is significantly associated with change in **Lean Mass.**
- Change in BMI is significantly associated with change in **% Body Fat.**

All associations remained significant after adjusting for age, sex, and diagnosis (DS vs non-DS).

LEAN MASS AND FAT MASS DO NOT CHANGE TO THE SAME DEGREE



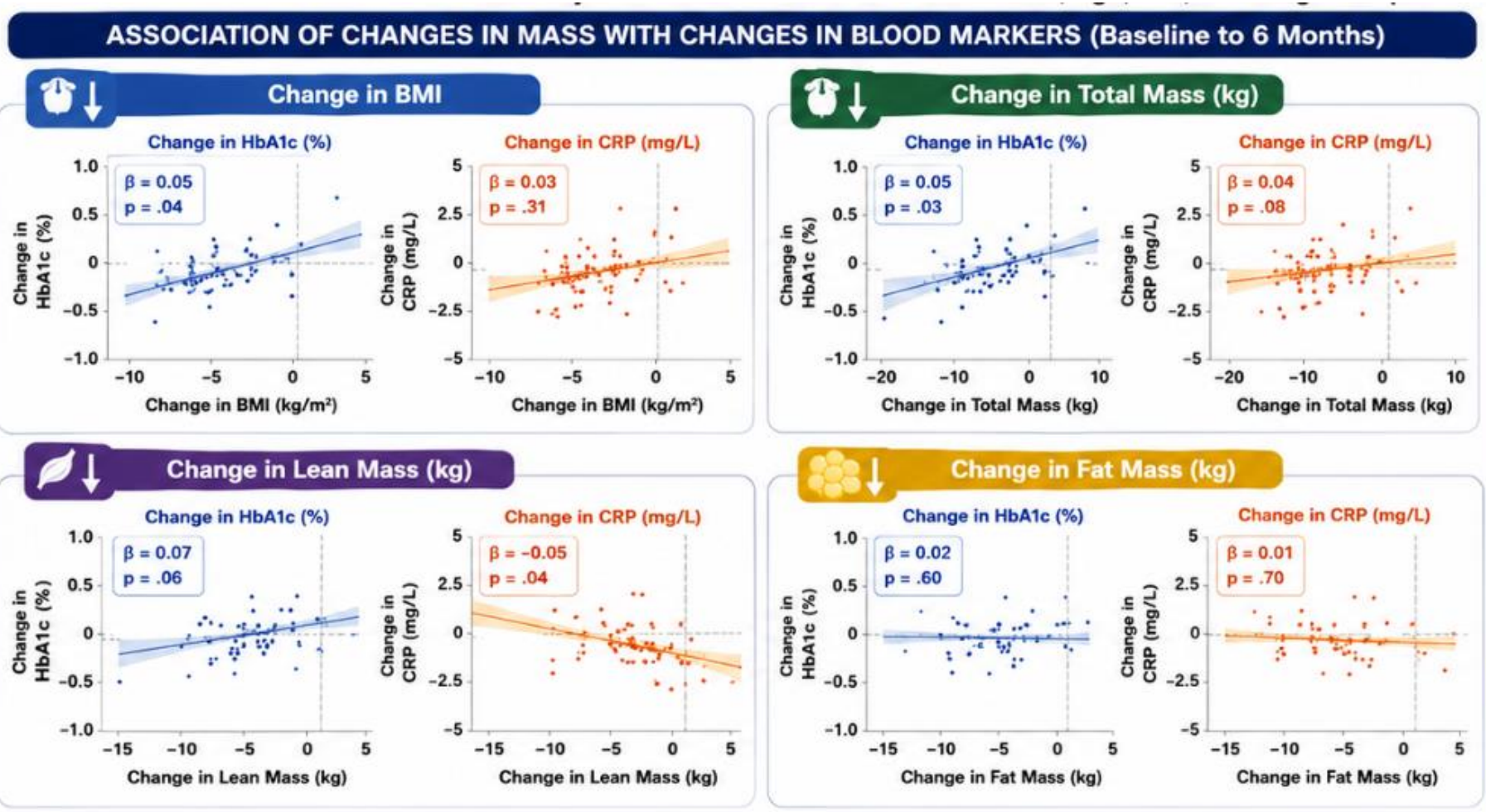
INTERACTION ANALYSIS
(Mass Type × Change in BMI)

The interaction between mass type (fat vs lean) and change in BMI was statistically significant.

$p < .001$

Fat mass changed substantially more than lean mass.
Weight loss was driven primarily by **reductions in adiposity** rather than loss of lean tissue.

Weight Loss Produces Meaningful Improvements in Body Composition



KEY FINDINGS

- Greater reductions in **BMI** were significantly associated with greater reductions in **HbA1c (p = .04)**.
- Greater reductions in **total mass** were significantly associated with greater reductions in **HbA1c (p = .03)**.
- Greater reductions in **total mass** were borderline associated with reductions in **CRP (p = .08)**.
- Greater reductions in **lean mass** were significantly associated with reductions in **CRP (p = .04)** and borderline with reductions in **HbA1c (p = .06)**.
- Changes in **fat mass** and **% body fat** were **not** associated with changes in **HbA1c** or **CRP**.

WHAT THIS MEANS

Weight loss was associated with improvements in **glycemic control** and **inflammation**—two key determinants of cardiometabolic health.

These improvements were seen with reductions in weight and lean mass, highlighting the importance of overall energy balance.

Key Findings

80% of adults with Down syndrome experience overweight and obesity

Preliminary evidence that weight loss may improve glycemic control and inflammation, while protecting muscle mass

Data supports weight management as a potential strategy to improve long-term health outcomes

Acknowledgements

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- Brian Helsel, PhD
- Amy Bodde, PhD
- Julianne Clina, PhD***
- Monica AhRens ***
- Keri Cox, BS

Down Syndrome Innovations of Kansas City
All the amazing families who agree to participate in our studies

Promoting healthy eating habits to support weight loss for patients with Down syndrome

Shannon Frizzell, MS, RD, LDN, CSOWM

Disclosures

- Shannon Frizzell does not have any disclosures.

Key recommendations:

- Address health conditions that can impact ability to be successful with weight loss goals:
  - Selective eating behaviors, hypothyroidism, sleep apnea, feeding and swallowing difficulties, etc.

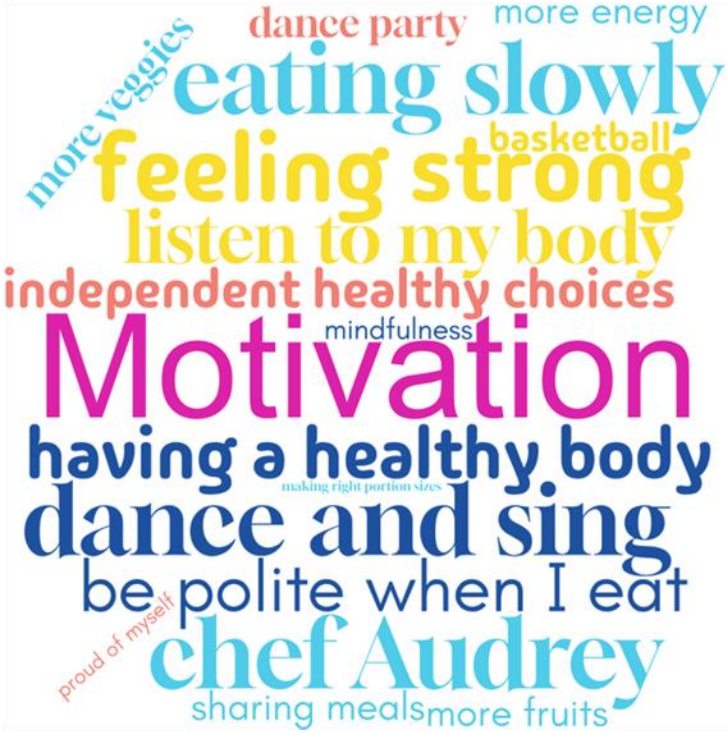
- Regularly assess dietary intake and physical activity
  - Identify opportunities for goal setting

- Implementation of nutrition interventions should be individualized
- Encourage healthy eating habits while avoiding over restriction

Assessing readiness and motivation

- Stages of change model:
  - Precontemplation > contemplation > preparation > action > maintenance
- Many patients are likely in the precontemplation or contemplation stages when beginning discussions around weight management and lifestyle goals
  - Goal: resolve ambivalence to behavior change
- Identify potential barriers to change
- Assessing motivating factors (positive and negative)
  - physical fitness goals, independence, body image, confidence, health factors/ chronic disease, etc.

Making motivation more visual:



Collaborative goal setting

- Each step of the goal setting process should be collaborative
  - Patient may have ideas for lifestyle change already
  - If patient is unsure, review dietary intake and offer options or ask permission to ask caregiver for ideas
  - As goals are achieved continue to reassess readiness and confidence to implementing additional goals

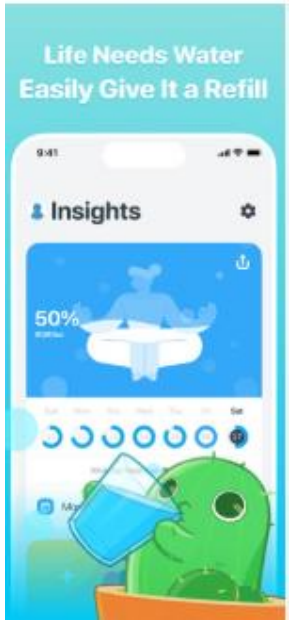
- Practice communicating goals to friends, family, coaches, co-workers, teachers
  - Write down what the patient wants to say together or with a parent/ caregiver, role play scenarios

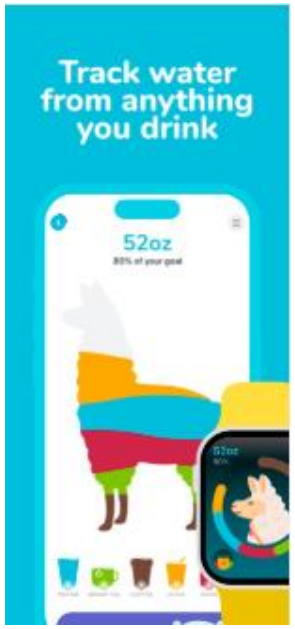
Self-monitoring

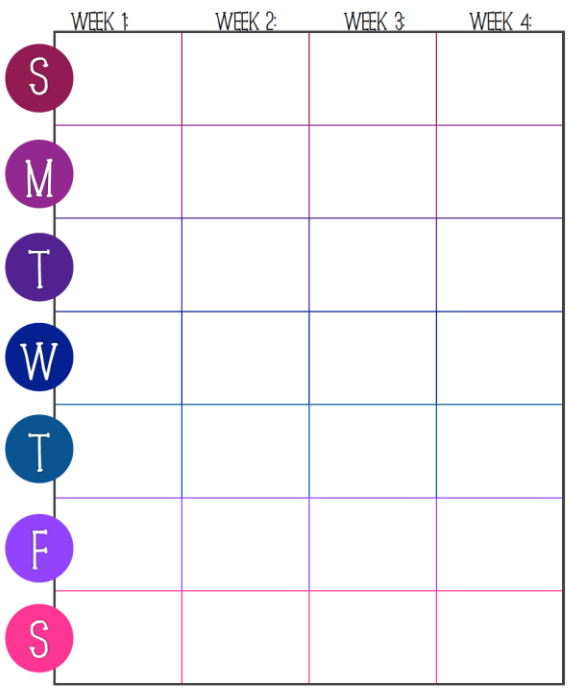
- The method(s) of self-monitoring selected ideally will be able to be completed by patient with minimal assistance

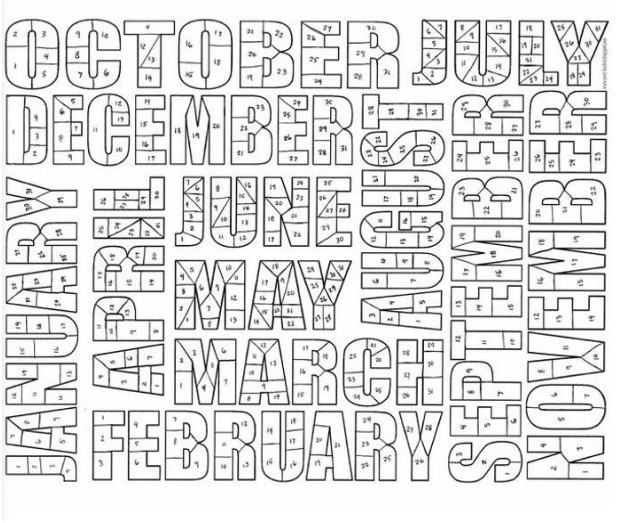
- Offer options for patient to select
  - phone reminders
  - virtual or printed goal tracking worksheets
  - photo food journals
  - wearable tech (ex: Fitbit watch)
  - progress photos/goal t-shirt or outfit

Self-monitoring









What does “meaningful” lifestyle change look like?

- Goals are individualized meaning this looks different for everyone – Just getting started is meaningful behavior change!
- How do we provide encouragement when results are slow?
- It is important to highlight that in the beginning stages of implementing lifestyle change goals may be small but building a routine will create opportunity to be successful.
- Slower progress or lack of progress leading to dissatisfaction may be a good opportunity to discuss AOM options.

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Support **adequate nutrition** and **prevent malnutrition** in patients with Down syndrome during treatment with weight loss medications.

Dominica Nichols, PhD, RD, LDN
MGH Down Syndrome Program

Disclosures

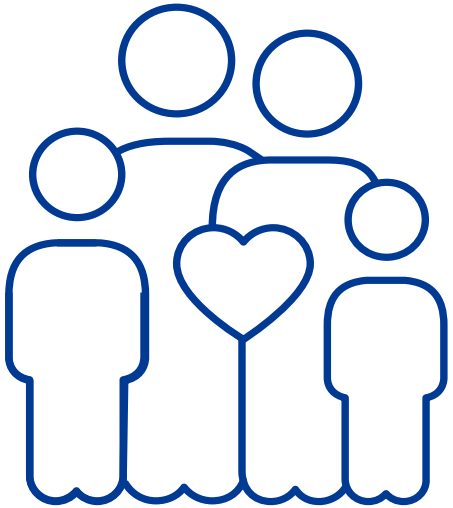
- Dominica Nichols owns stock in Abbott, a company that manufactures nutrition products for retail, hospital, and home use. She does not consult for them or any other equivalent commercial or pharmaceutical entity.

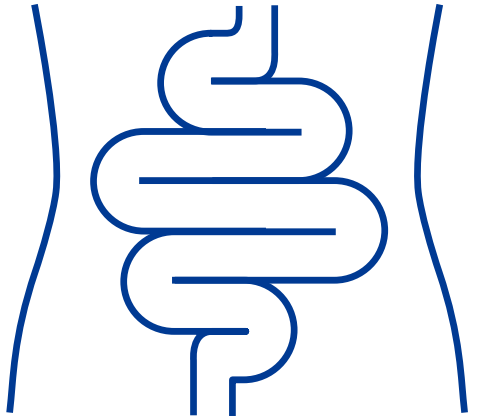
- We will not be talking about any specific nutrition products today.

Feeding (Eating) and Nutrition are two sides of the same coin.

- What an individual eats and drinks is important
- How an individual eats and drinks is important
- Maximizing quality of life and health are also important

Feeding Challenges and Opportunities:





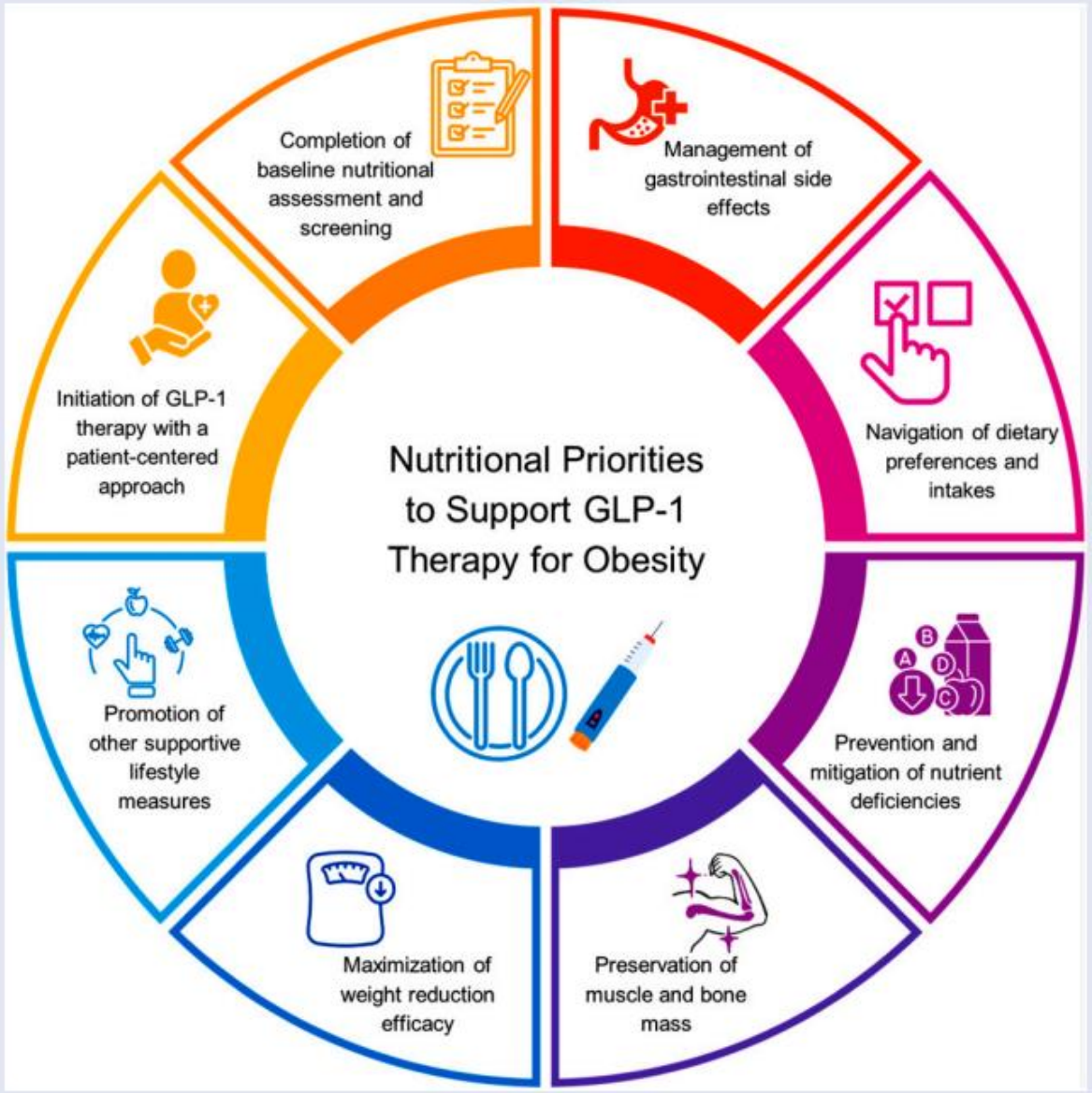
- modified textures or consistencies
- sensory-seeking or sensory-avoiding behaviors
- oral aversion

Nutrition Challenges and Opportunities:

- “age-appropriate” nutrition and hydration
- desire for sameness, routine and “expected” outcomes
- competing priorities and various food environments (home, school, medical services, community, family)
- food as a motivator or a "threat" - are specific foods and drinks part of a person's behavior plan?

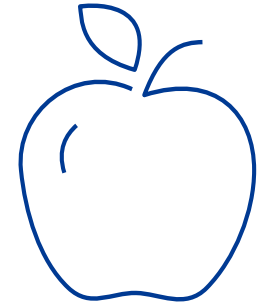
Figure 1.

Key elements of nutritional priorities to support GLP-1 therapy for obesity.



[Mozaffarian D, Agarwal M, Aggarwal M, et al. Nutritional priorities to support GLP-1 therapy for obesity: a joint Advisory from the American College of Lifestyle Medicine, the American Society for Nutrition, the Obesity Medicine Association, and The Obesity Society. The American Journal of Clinical Nutrition. Published online May 30, 2025.]

Common Nutritional Problems:



Nutritional Problem	Potential Consequences
predicted appetite changes with medications: ANOREXIA	**protein-calorie malnutrition**
	micronutrient malnutrition
Inadequate Protein Intake	Lethargy ("tiredness") => skin breakdown
Iron deficiency Iron Deficiency Anemia	Cognitive Change or Lethargy ("tiredness")
Dietary Calcium Deficiency Excess Dietary Calcium	Osteopenia or Osteoporosis Drug-Nutrient Interactions, Constipation
Dietary Fiber Deficiency Inadequate Fluid Intake	Constipation, Diarrhea, Reflux, Emesis

Common Nutritional Problems:

Nutritional Problem	Potential Consequences and Challenges
Restrictive Diets	Meals require more planning. **Resistance** to adopting new eating approaches: • **desire for sameness** and consistent routine(s) • dealing with the **social pressure** to eat more/similar to before treatment with medication Caregiver **resistance** to supporting new eating approaches: • comfort with **consistent routine(s)** • **fear** of managing symptoms that may overlap with acute illness

Adequate Nutrition across the Lifespan

*"**Malnutrition** is associated with adverse health outcomes, including faster cognitive and functional decline."* (Loda et al. 2024)

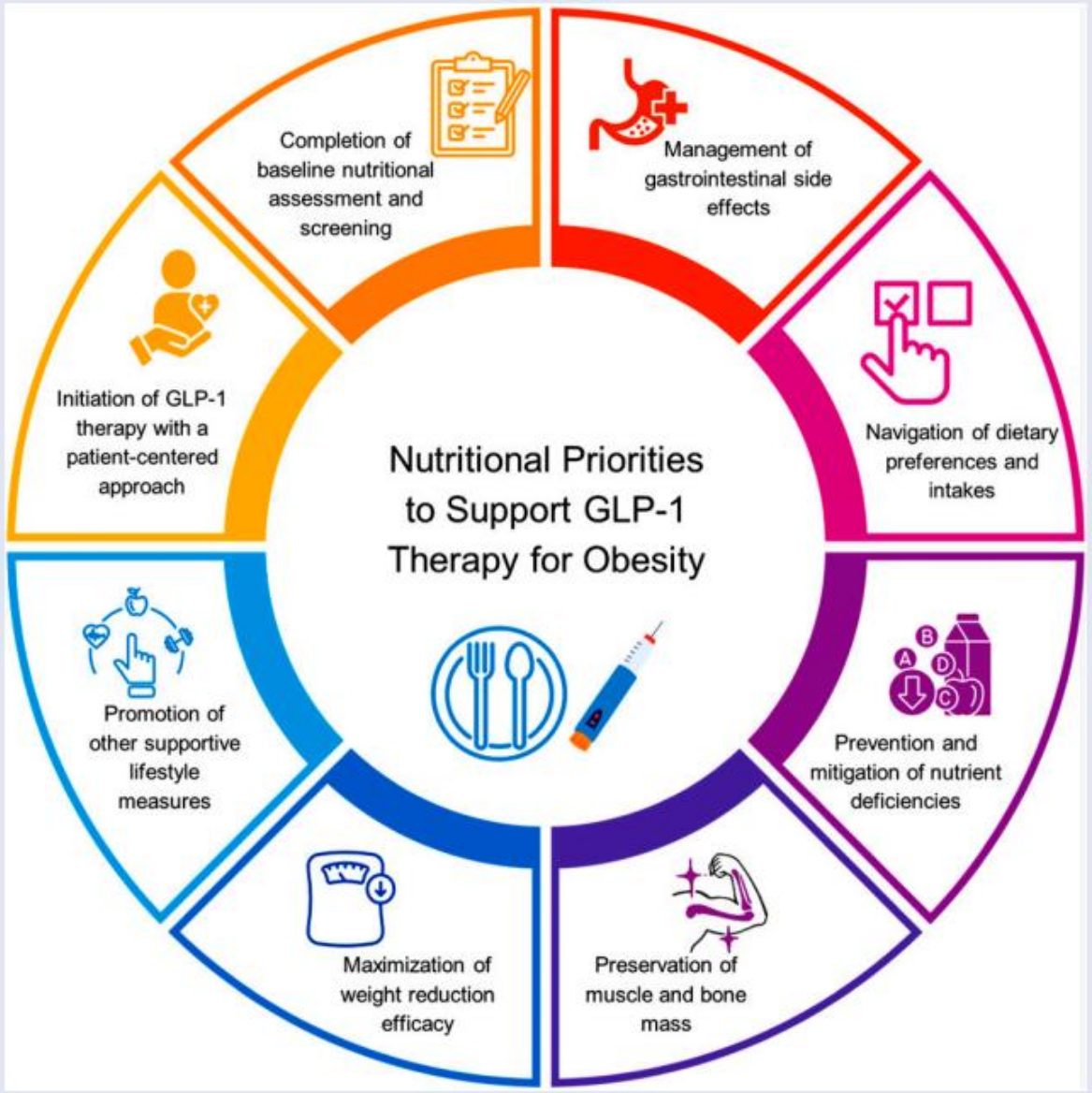
Malnutrition is not defined by weight or weight changes in alone.

- Micronutrient malnutrition can lead to "adverse health outcomes" without changes in overall body appearance.
- Macronutrient deficiencies can also lead to "adverse health outcomes."

www.wayfair.com

Figure 1.

Key elements of nutritional priorities to support GLP-1 therapy for obesity.



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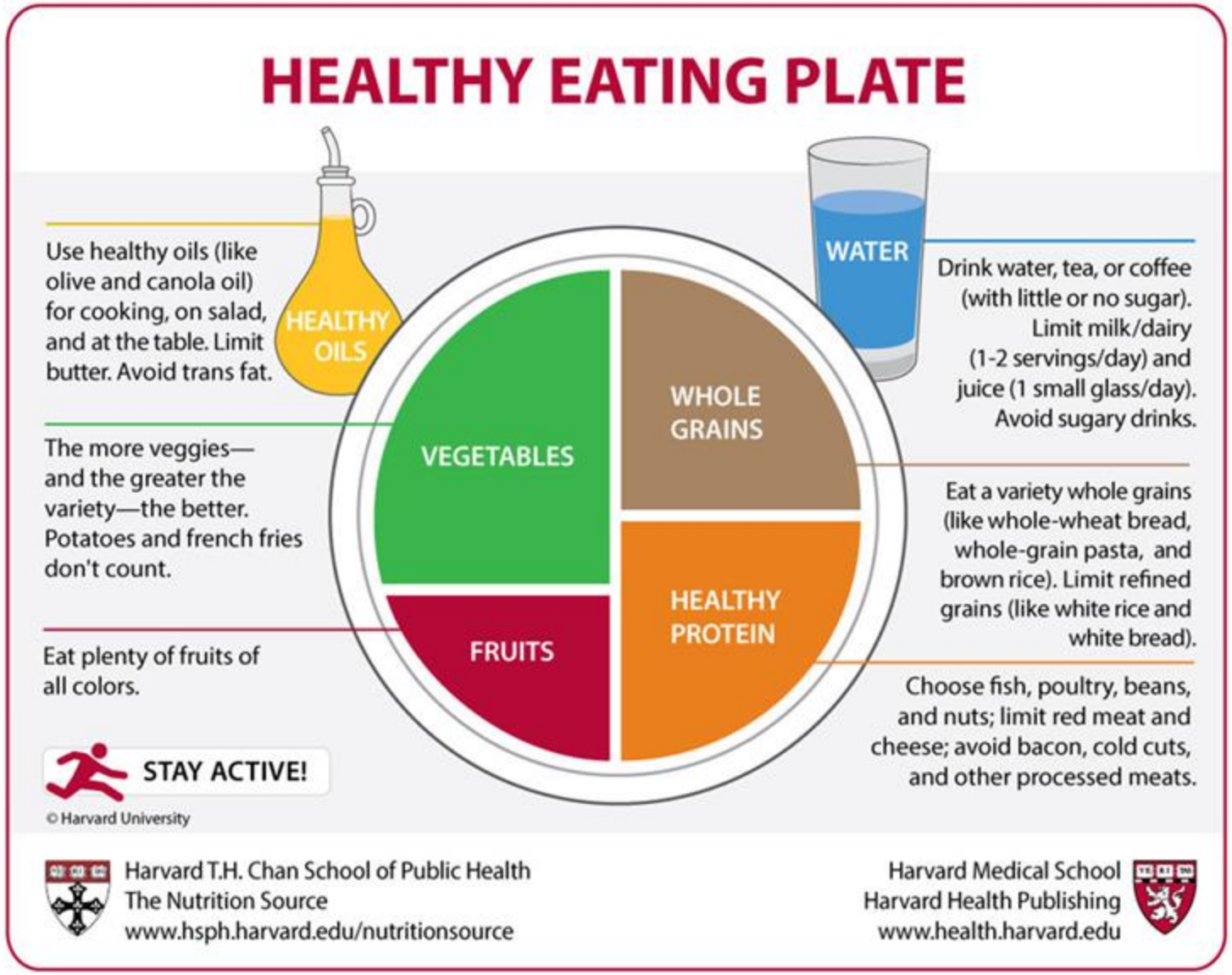
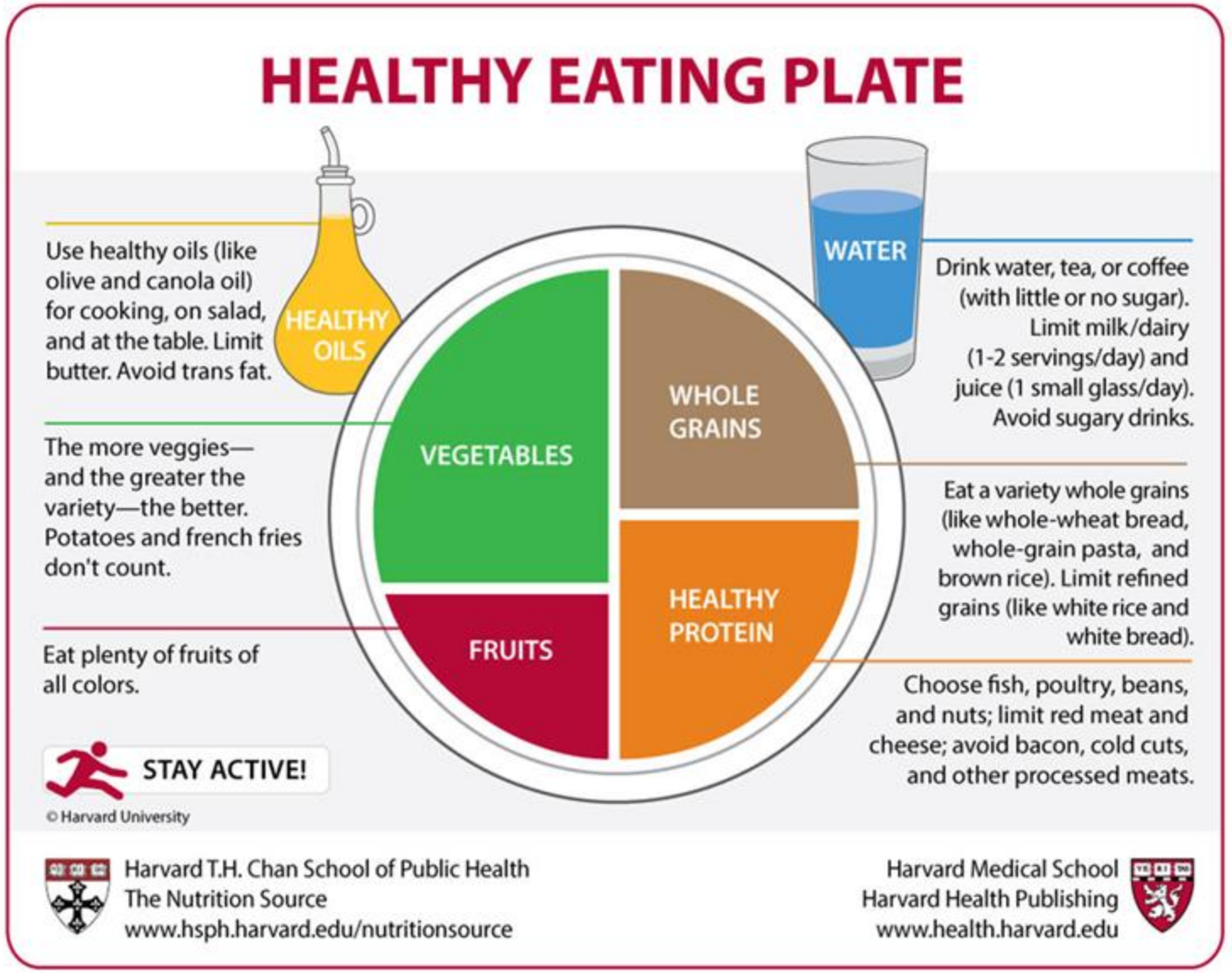
Nutrition is not Unique; Eating Strategies Might Be

mindbodygreen.com



Nutrition is not Unique; Eating Strategies Might Be

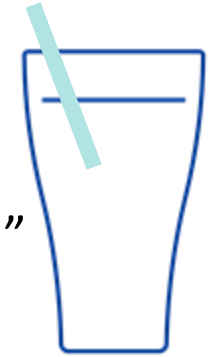
futureceuticals.com (based on CDC and USDA data)

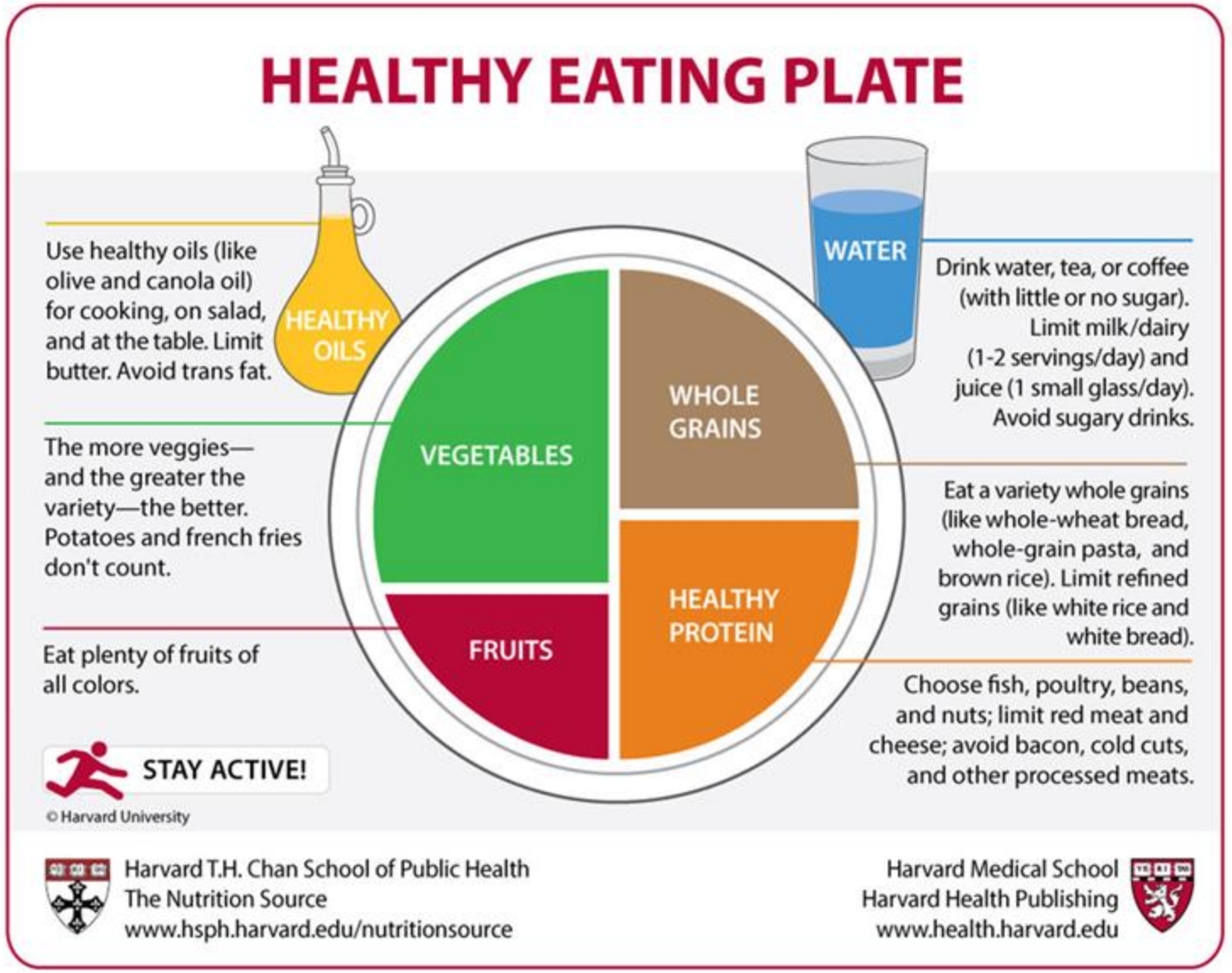


Nutrition is not Unique; Eating Strategies Might Be

eatsmartidahointhekitchen.com

"Water is the BEST drink."
"Water is an anytime drink."





Nutrition is not Unique; Eating Strategies Might Be

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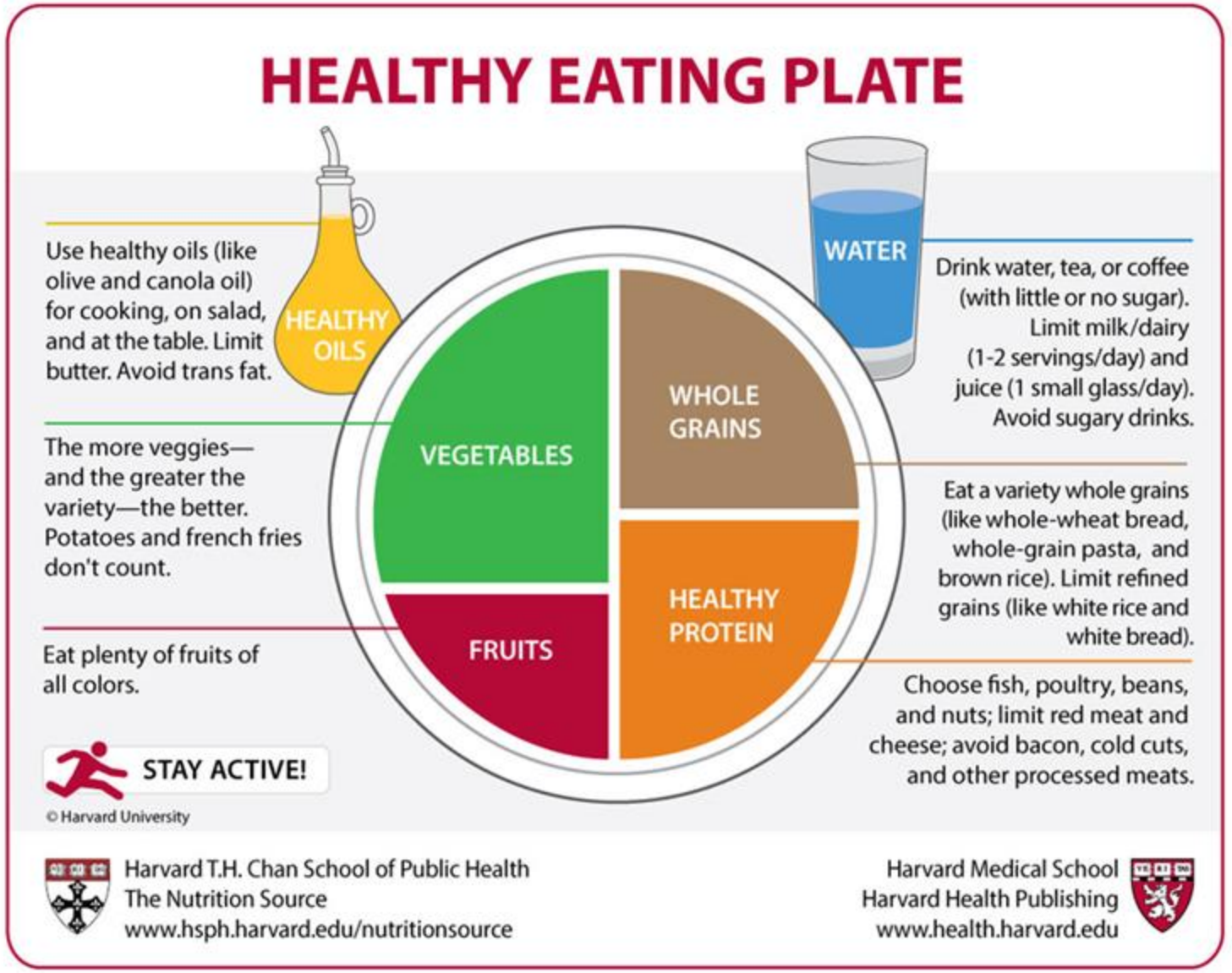

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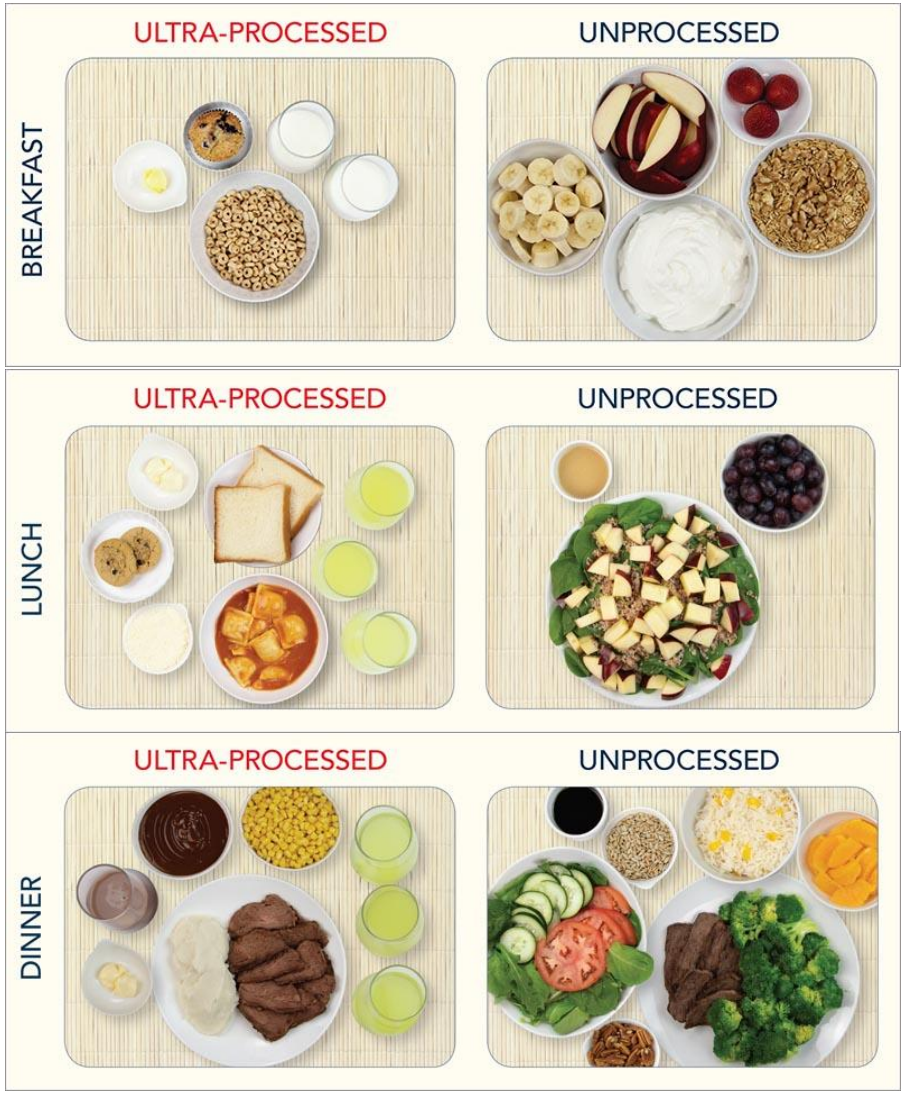
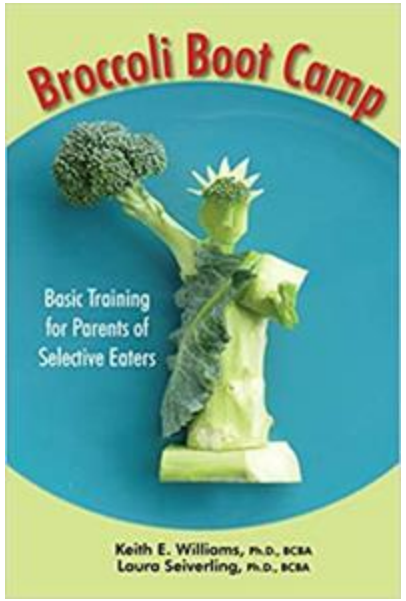
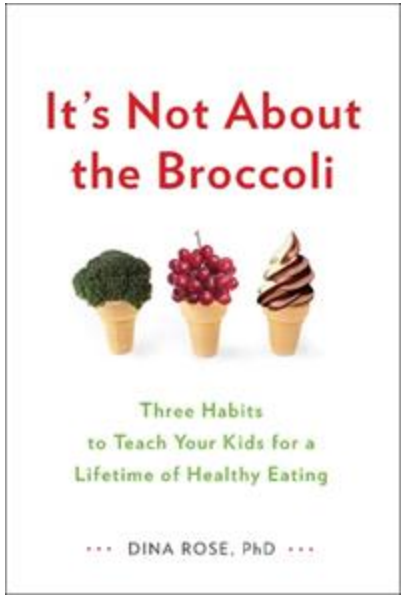
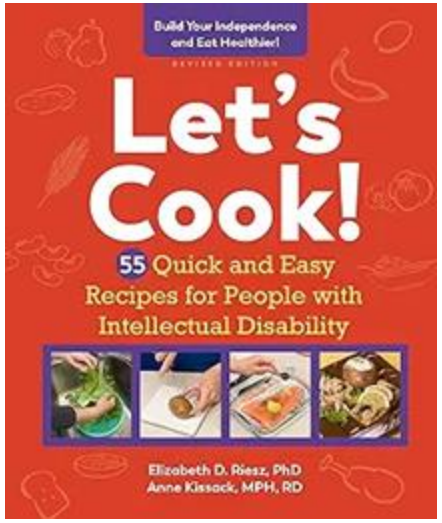
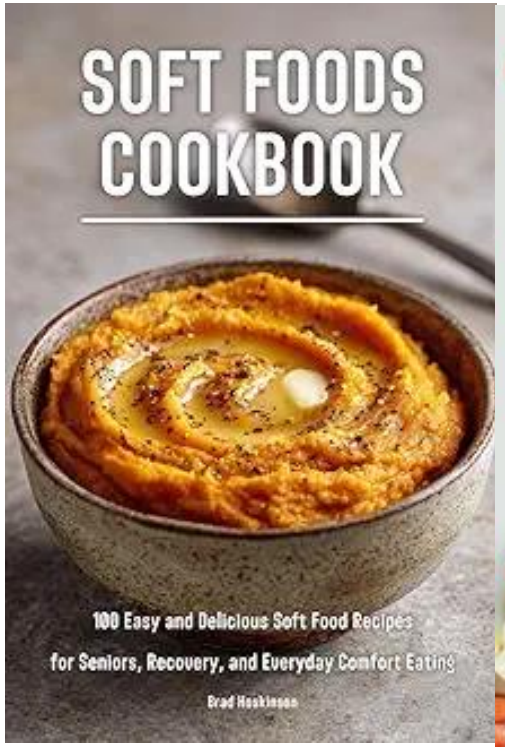


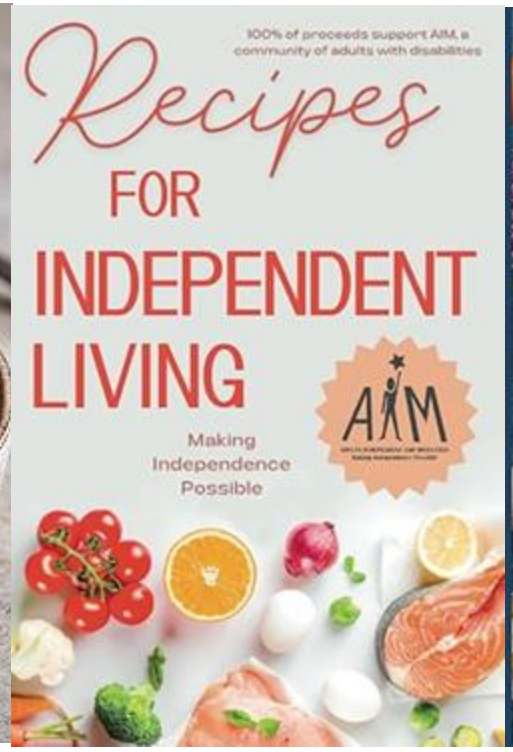
Nutrition is not Unique; Eating Strategies and Tools Might Be

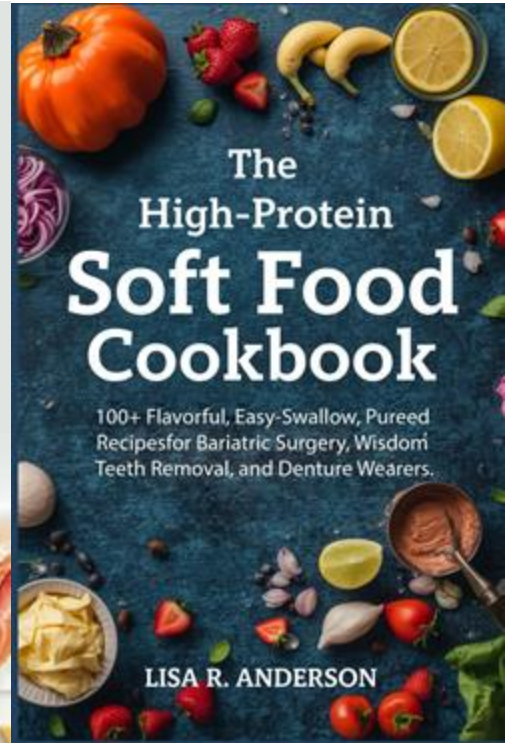












Tips for Success:

- Use **positive language** when talking about food and bodies.
- **Portion snacks and foods in advance.** Color-coded (food prep) containers can be helpful, or consider choosing a snack container (with a top) that can be the "right size" for most snack choices.

- Start small; be specific! **Develop a healthy eating goal** that includes alternatives to food-based (or drink-based) rewards in education (IEP), transition, or individualized support plans (ISP).
- **Develop behavior plans that do not use food as a reward.** Document and discuss specific alternatives to food-based rewards.

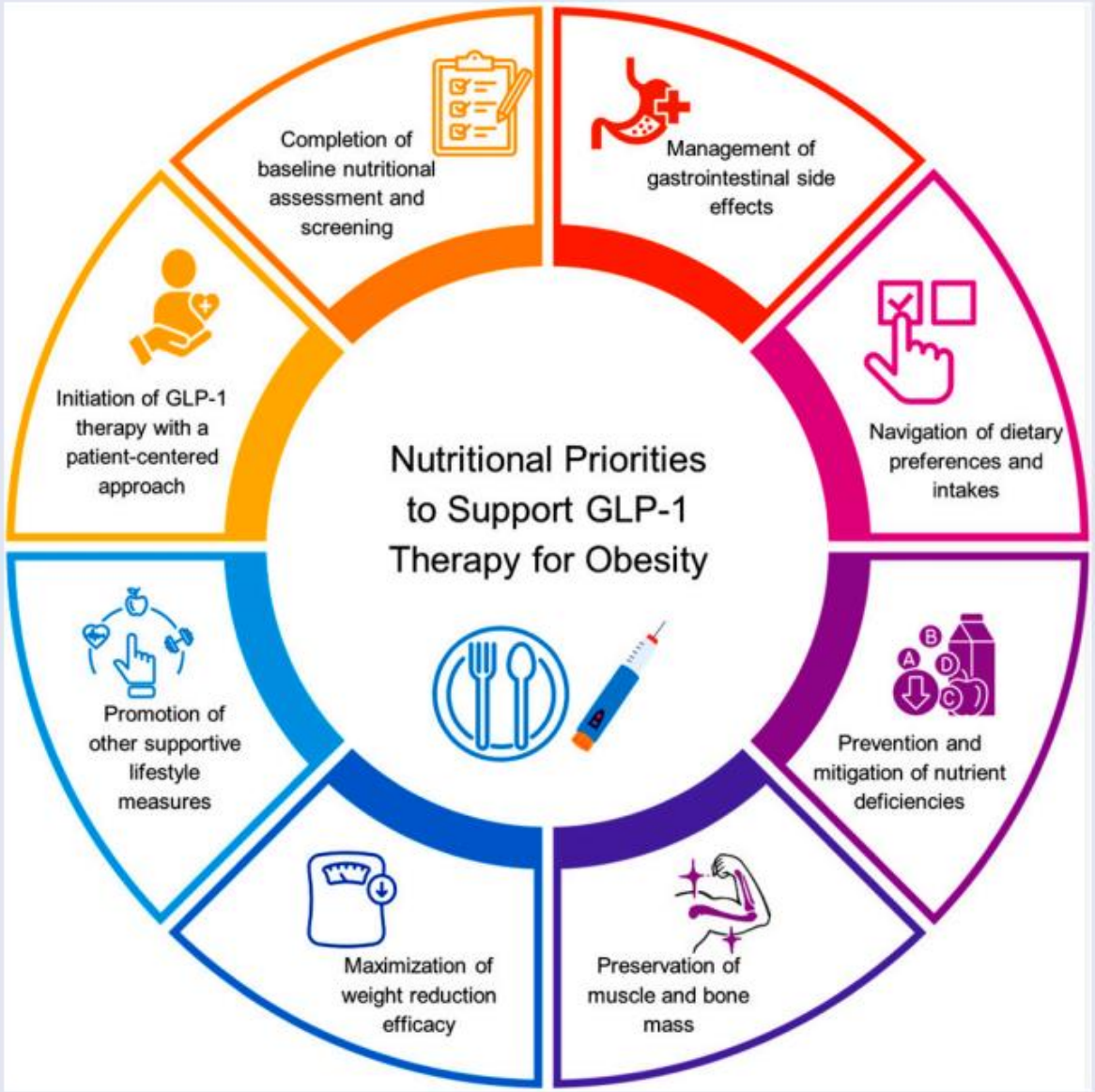
More Tips for Success:

- Review the **mechanisms** of hunger and satiety with patients and caregivers using visual supports.
- Review any risks for diarrhea, constipation, or reflux with proposed medication regimen.

- When possible, **connect** patient and their caregivers **with a nutrition professional** to assess for any nutritional deficiencies before and during treatment. Encourage on-going support.
- In partnership with a nutrition professional, identify nutritional gaps and find solutions to bridge them with food, drinks, and/or supplements.

Figure 1.

Key elements of nutritional priorities to support GLP-1 therapy for obesity.



Medical and Nutritional Implications of GLP-1 agonist-supported Weight Loss in Down syndrome

- Health Benefits and Nutrition Implications of Weight Loss in Down syndrome
  - Lauren Ptomey, PhD, RD, LD
  - Shannon Frizzell, MS, RD, LDN, CSOWM
  - Dominica Nichols, PhD, RD, LDN

- Medical and Surgical Management of Obesity in Down syndrome
  - Asef Mahmud, MD, FACP, FAAP, DABOM
  - Vibha Singhal, MD, MPH, DABOM
  - Dominica Nichols (moderator)