Weight Management Strategies for Individuals with Intellectual and Developmental Disabilities

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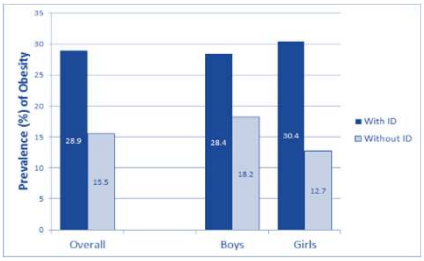
Healthy Weight Research Network | Children with Autism Spectrum Disorder & Developmental Disabilities

Disclosures

- Linda Bandini
  - None
- Lauren Ptomey
  - None

What do we know about obesity in individuals with intellectual and developmental disabilities?

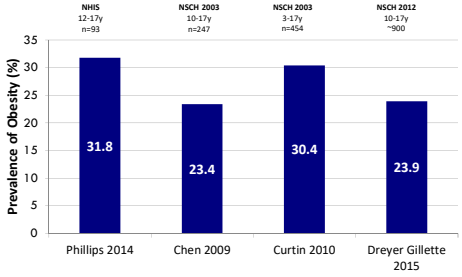
Prevalence of obesity among 10-17 year olds with and without intellectual disability (ID) from a nationally representative sample*



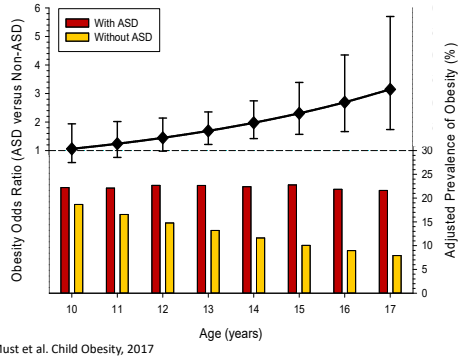
Segal et al., *Disability and Health J*, 2016

*from NSCH 2011/2012; n=672 with ID

Prevalence of obesity among children with ASD from nationally representative samples



Prevalence of obesity in youth ages 10-17 with and without with ASD, NSCH 2011



Must et al. Child Obesity, 2017

Prevalence of obesity in adults with intellectual disabilities

US National Study (Hsieh K,J Int Dis Res,2014)

- Overweight 28.9%
- Obesity 38%

International Review (Ranjan S et al, J Appl Res Int Disabil, 2017)

- Overweight 28-71%
- Obesity 17-43%

Individuals with IDD have the same risk factors as typically developing peers but may also have additional risk factors.

Potential unique risk factors for obesity in youth and adults with intellectual and developmental disability

Energy intake

- Food selectivity
- Oral motor problems
- Sleep
- Medication
- Behavior problems
- Food as a reward

Energy expenditure

- Altered body composition
- Delayed/impaired motor function
- Barriers to physical activity

Why weight management?

- Individuals with IDD are at greater risk of obesity related comorbid conditions compared to the general population
- Co-morbid conditions may limit opportunities for independent living

Creon et al, Autism 2015, Young-Southward et al , Jnt Disabil Res, 2017, Cooper et al, J Appl Res Intellect Disabil, 2018

If an individual with IDD wants to lose weight to improve their health they should be allowed that choice.

If weight loss is not a priority, we should respect their decision

Weight Management Interventions in Youth with IDD

Research on weight management programs for youth with IDD

AuthorJ	Intervention	Participants	Age Range	Length of study	Outcome
Curtin et al., J Pediatrics, 2013	Family based Nutrition education vs Nutrition education and behavioral intervention	Down Syndrome (n=21)	13-26 years	6 month active intervention	Significant weight loss in the group who received the education plus behavioral intervention but not in the education only group
Dreyer-Gillette et al., Childhood Obesity, 2014	Weight management program adapted for children with special needs	Down syndrome, ASD, IDD, PWS, (n=76)	2-19 years	Visits once a month for first 3 months and then 12 month	Decrease in BMI z reported
Ptomey et al., J Academy Nutrition and Dietetics, 2015	Comparison of two diets-Enhanced stop light or conventional diet and feasibility of tablets as a weight loss tool	IDD (n=20)	11-18 years	2 month study	Significant weight loss in both groups. Enjoyed use of the tablets.

Health U: a family-based weight loss intervention for youth with IDD

Supported by NIDDK, S; NICHD, R01HD072573-01

Health U. Philosophy

- Focus on healthy eating and physical activity, not on dieting and calories
- Adolescents with IDD need a program tailored to their literacy needs so they can access the information themselves
- Parent and child attend nutrition education sessions together
- Lifestyle modifications to provide support and encouragement for making behavior change

Program Structure

First 45 minutes

Nutrition & PA Education

Families meet together to learn about healthy eating and physical activity

YOUTH:

- *fun physical activity*
- *taste tests*

Led by RD

PARENTS:

Behavioral Intervention

Led by lifestyle coach

Education: Nutrition & Activity Session Features Adaptations for IDD Population

- **Lectures** – *very brief*
- **Instructions** – clear and simple, *telling*
- **Demonstrations** - *showing*
- **Practice** – hands on, *doing*
- **Materials**
  - Food models
  - Pictures
- **Games** – active participation
- **Taste tests**
- **Feedback and praise** – lots!

Concepts of the healthy eating plans are reinforced in each session

Physical activity monitoring

- Pedometers are provided to encourage walking
- At the start of the group session participants share their step counts for the week

Healthy Eating Plan

A tool to guide healthy eating

- Simple, based on servings of food
- Presented in a pictorial manner
- Individualized plan for each participant
- Does not require mathematical ability
- Avoids restrictive approach to dieting
- Provides flexibility

Weems et al , J Acad Nutr Diet, 2017

HEALTHY EATING PLANS

Overview:

- Food Guide
  - 6 food groups
  - Always vs. Once in A While Foods
  - Treats
  - Mixed Dishes

Weems et al , J Acad Nutr Diet, 2017

Healthy Eating Plans

Weems et al.
J Acad Nutr Diet, 2017

Healthy Eating Plans

- Servings
  - 1 square = 1 serving
  - Standard ***serving size*** and ***type*** of food

=

Weems et al , J Acad Nutr Diet, 2017

ALWAYS vs. ONCE IN A WHILE

- ALWAYS foods represent the healthiest choices within each food group.
- ONCE IN A WHILE foods contain more calories, fat or added sugar.

Skim and 1% milk
= ALWAYS

Whole and 2% milk
= ONCE IN A WHILE

Weems et al , J Acad Nutr Diet, 2017

Healthy Eating Plans

ALWAYS vs. ONCE IN A WHILE

Boneless chicken breast
= ALWAYS

Drumstick with skin
= Once in a while

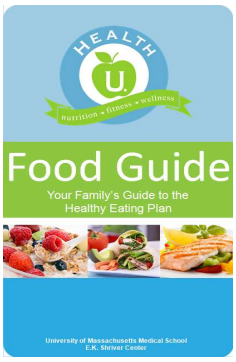
Discretionary Calories

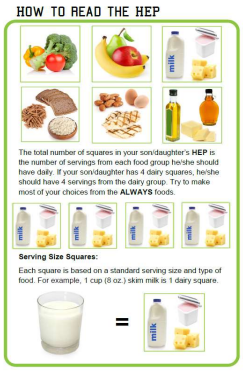
Participants given 8 coins per week
(50 kcal/coin) to use for "treats"

Discretionary Calories

Teaching parents how to use the Healthy Eating Plans

- Introduce the parent to the food-based Healthy Eating Plan
- Review serving sizes
- Always vs. Once In A While foods
- Discretionary calories (coins)





Building A Meal

1 oz. Turkey Breast
2 slices whole wheat bread
Lettuce, tomato, onion, 1 Tbsp. mustard

¾ cup non-fat yogurt
1 cup strawberries

Physical activity

- Engage participants in fun physical activities
- Introduce new ways to be physically active

"Taste Tests"

- Designed to encourage students to try new foods
- Presented in unique, fun, and appealing ways
- Social norm is to try the food
- Students rate how well they like the food



TASTE TEST

Name: _____ Date: _____

Today we learned about:

_____

_____.

Today I tasted: _____.

I thought:

I liked it!	It's OK	I might like it next time.

I'm going to try

_____

at home this week.

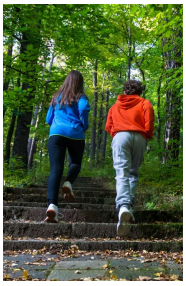
Behavioral Intervention: Why so important?

- Education alone: not expected to translate to behavior change at home, which is needed for weight loss
- Eating and activity patterns at home: firmly established, family-specific, and hard to change
- Environments (home, school, community): present *both* barriers and opportunities to be addressed over time
- Parents need to learn, practice, and receive feedback on strategies to establish lasting health behavior changes

Behavioral Intervention

- Parents learn behavioral procedures to facilitate lifestyle change with son or daughter
- Taught in 45 min parent-only sessions, led by lifestyle coach:
  - Discuss challenges and successes from previous week
  - Review and discuss homework completion
  - Get new information on behavioral procedures
  - Practice, using procedures
  - Receive new homework

5 Behavioral Intervention Procedures



- ***Monitoring*** eating and physical activity (PA) – daily
- ***Goal setting*** to promote healthy eating and increase PA – weekly
- ***Positive reinforcement*** to support and encourage healthy choices and goal achievement
- ***Assessing and changing daily environments*** to remove barriers and promote healthy behaviors
- ***Behavioral contracting*** to clarify reciprocal parent and child expectations

Summary of Health U

- Provides peer support for parents and adolescents
- Adolescents learn how to monitor eating and activity
- Adolescents participate in goal setting
- Parents use supportive behavioral techniques to encourage healthy behaviors and adherence to Healthy Eating Plans

- Attendance is very good
- Families have provided positive feedback

Health U Research Team

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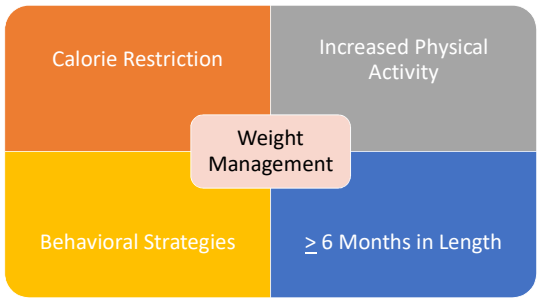
Weight Management Interventions in Adults with IDD

Weight Management in Adults with IDD

- Only ~22 trials looking at weight management in adults with IDD
  - 95% of which were not conducted in accordance with current weight management guidelines which recommend a multicomponent approach.
  - Thus on average they reported minimal weight loss 3%.

Multicomponent approach



Multicomponent Weight Management Interventions

Study	Diet	N	Length	Results
Melville et al	Conventional Diet	47 adults	26 weeks	Lost >5%: 36%
Harris et al	Conventional Diet Waist Winners Too	50 adults	6 mos loss 6 mos maintenance	Lost >5%: 50% Lost >5%: 21%
Martinez-Zaragoza et al.	Conventional Diet	33 adults	17 weeks	8 kg
Saunders et al.	eSLD	66 adults	6 mos loss 6 mos maintenance	-6.4% at 6 mos -8.7% at 12 mos
Ptomey et al	eSLD Conventional Diet	149 adults	6 mos loss 12 mos maintenance.	Weight Loss eSLD: -7% ; 63% lost >5% CD: -3.8%; 40% lost >5% Maintenance eSLD: 6.7%; 57% lost >5% CD: 6.4%; 48.9% lost >5%

Conventional Diet

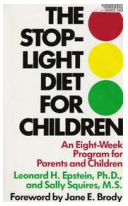
- A conventional reduced energy diet (CD) is recommended by the Academy of Nutrition and Dietetics (AND) and the NHLBI Guidelines.
  - Reducing energy intake by 500-750 kcals/day
  - Reducing portion size
  - <30% of energy from fat
  - Increasing fruits and vegetables
  - Results in 1-2 lbs loss per week

Limitations of CD

- Requires calorie counting
- Reading nutrition labels
- Meal prepping
- Reliance on caregiver
- Comprehending education materials

Enhanced Stop Light Diet

- Enhances the Original Stop Light Diet with Portion Controlled Meals (PCMs) and 5 servings of fruits and vegetables per day.



Original Stop Light Diet

- Categorizes foods according to energy content
  - Red
  - Yellow
  - Green
- Grade 1 (strong, consistent supporting evidence) for its effectiveness in weight management.
  - The Academy of Nutrition and Dietetics Evidence Analysis Library

Epstein L, Squires S. *The Stoplight Diet for Children: An Eight-Week Program for Parents and Children.* Boston: Little Brown & Co; 1988.

Original Stop Light Diet

- Categorizes foods according to energy content
  - Red
  - Yellow
  - **Green (Low Energy)**



Epstein L, Squires S. *The Stoplight Diet for Children: An Eight-Week Program for Parents and Children.* Boston: Little Brown & Co; 1988.

Original Stop Light Diet

- Categorizes foods according to energy content
  - Red
  - **Yellow (Moderate Energy)**
  - Green



Epstein L, Squires S. *The Stoplight Diet for Children: An Eight-Week Program for Parents and Children.* Boston: Little Brown & Co; 1988.

Original Stop Light Diet

- Categorizes foods according to energy content
  - **Red (High Energy)**
  - Yellow
  - Green



Epstein L, Squires S. *The Stoplight Diet for Children: An Eight-Week Program for Parents and Children.* Boston: Little Brown & Co; 1988.

Original Stop Light Diet

- **Grade 1 (strong, consistent supporting evidence) for its effectiveness in weight management for children**
  - The Academy of Nutrition and Dietetics Evidence Analysis Library

Academy of Nutrition and Dietetics. What is the evidence to support using the Traffic Light Diet to limiting calorie and food intake in children? 2005; http://www.adaevidencelibrary.com/conclusion.cfm?conclusion_statement_id=250052

Portion Controlled Meals

- High volume, low energy prepackaged meals
  - Convenient and Decision Free

Grade 1 evidence for their effectiveness in weight management

Weight Loss And Maintenance For Individuals With Intellectual And Developmental Disabilities

Donnelly (PI)
R01 DK083539

Design Overview

- 18 month intervention: 6 month weight loss, 12 month maintenance
- 149 adults with IDD
  - Each adult had a designated caregiver called a study partner
- Participants randomized to either an enhanced stop light diet (eSLD) or a conventional diet (CD)
- Recommended to obtain 150 mins/wk of physical activity
- Monthly, in-home meeting with a health educator.
- Track food (icons), steps, and activity.

Participants

Inclusion Criteria

- 18 + years of age
- Mild to moderate IDD
- BMI > 25 kg/m^2
- Able to walk
- Ability to communicate through spoken language

Exclusion Criteria

- Insulin dependent diabetes
- Participated in a weight reduction program in the past 6 months
- Treatment for major depression or eating disorders
- Consuming special diets
- Prader-Willi Syndrome
- Pregnant, planning on becoming pregnant, or became pregnant during the study

Diet Groups

eSLD

CD

Stoplight Guide

STOP LIGHT FOOD RATINGS

- LOW CALORIE – *EAT PLENTY OF THESE!*
- SOMEWHAT MORE CALORIES – *GO EASY ON THESE!*
- EVEN MORE CALORIES – *LIMIT & AVOID EATING THESE!*

VEGETABLES:

- ASPARAGUS
- BEANS: GREEN & YELLOW
- BEETS
- BROCCOLI
- CABBAGE
- CARROTS
- CAULIFLOWER
- CELERY
- CUCUMBER
- LETTUCE
- MUSHROOMS
- ONIONS
- PEAS
- PEPPERS
- SPINACH
- SQUASH
- TOMATOES
- ZUCCHINI

- BEANS (WHITE, GARBANZO, BLACK)
- CORN
- LENTILS
- POTATOES (BAKED/MASHED)
- SWEET POTATOES (BAKED/MASHED)

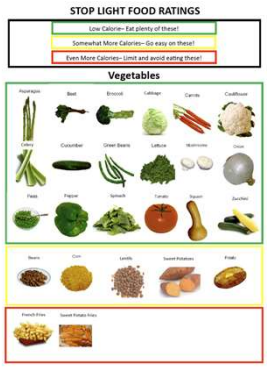
- POTATOES (FRIED)
- SWEET POTATOES (FRIED)

FRUIT:

- APPLES
- APRICOTS
- BLUEBERRIES
- BLACKBERRIES
- CANTALOUPE
- CHERRIES
- GRAPEFRUIT
- GRAPES
- HONEYDEW MELON
- KIWI
- MANGO
- NECTARINES
- ORANGES
- PEACHES
- PEARS
- PINEAPPLE
- PLUMS
- POMEGRANATES
- RASPBERRIES
- STRAWBERRIES
- TANGERINES
- WATERMELON

- BANANAS
- CANNED FRUIT
- DRIED FRUIT

Visual Stop Light Guide



Weight Charts

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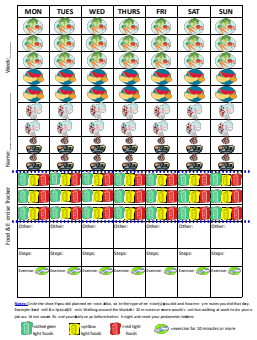
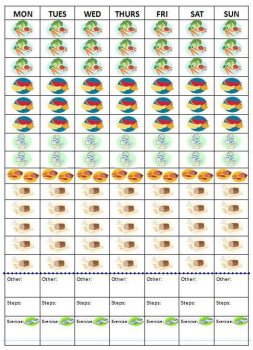
Intake Tracking Form eSLD



Intake Tracking Form CD

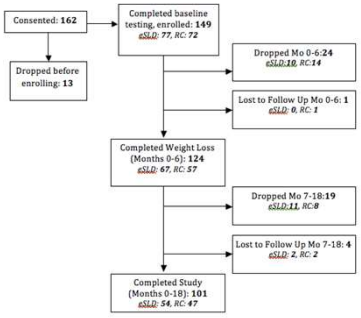


Game Board

Monthly Meeting

- 24-hour food recall
- Review Tracking Sheet
- Review goals from previous visit
- Give feedback, recommendations, positive reinforcement
- Review any barriers
- Set new goals
- Give rewards
- Weigh-in (optional)

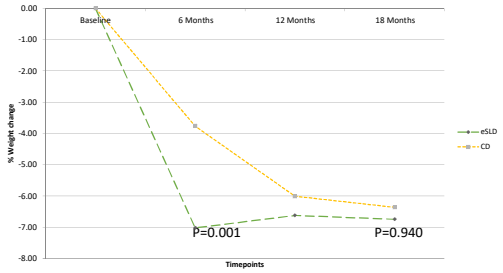
Consort Diagram



Subjects

	Total Sample (n=149)	eSLD (n=77)	RC (n=72)
Age	36.5 ±12.2	36.1± 12.0	37.0±12.5
Gender			
Male	64 (43%)	31 (48.4%)	33 (51.6%)
Female	85 (57%)	46 (54.1%)	39 (45.9%)
Race			
White	125 (83.9%)	66 (52.8%)	59 (47.2%)
African American	19 (12.7%)	8 (42.1%)	11 (57.9%)
Asian	2 (1.3%)	1 (50%)	1 (50%)
Native American or Alaska Native	1 (0.7%)	1 (100%)	---------
Two or more Races	2 (1.3%)	1 (50%)	1 (50%)
Education Level			
Less than 9th grade	5 (3.4%)	3 (60%)	2 (40%)
9th-12 grade	21 (14.1%)	10 (47.6%)	11 (52.4%)
High school or GED	94 (63.1%)	52 (55.3%)	42 (44.7%)
Post graduate classes	29 (19.5%)	12 (41.4%)	17 (58.6%)

% Weight Change



Change in dietary intake based on 3-day food records

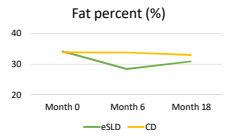
	Baseline		6 months			18 months		
	eSLD	CD	eSLD	CD	p	eSDL	CD	p
Energy intake (kcal/day)	1753±533	1847±818	-352±514	-238±964	0.48	-303±612	-220±612	0.59
Fat (% energy intake)	34.1±6.5	33.8±6.8	-5.3±10.8	-2.5±10.6	0.16	-2.7±11.1	1.5±4.9	0.09
Fruits (Servings/day)[a]	1.3±1.7	2.1±2.1	-0.3±1.8	-0.2±2.6	0.75	-0.5 ±2.0	-0.6±2.2	0.90
Vegetables (Servings/day)[a]	2.5±1.4	3.0±1.7	-0.1±2.2	-0.1 ±2.3	0.64	-0.1±1.9	-0.2±2.4	0.80
Portion controlled entrees (number/day)[b]	0.3± 0.5	NA	0.4 ±0.7	NA	NA	0.3±0.7	NA	NA
Portion controlled shakes (number/day)[b]	0.0±0.1	NA	0.9±0.8	NA	NA	0.1±0.4	NA	NA
Stop Light green foods (number/day)[b]	2.6 ±1.6	NA	1.0±2.5	NA	NA	0.6±2.5	NA	NA
Stop Light red foods (number/day) [b]	5.3±1.9	NA	-2.5 ±2.2	NA	NA	-1.6±2.7	NA	NA

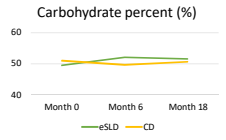
eSLD = enhanced Stop Light Diet, CD= conventional diet, NA=not applicable

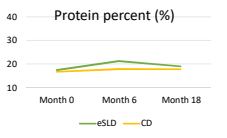
[a] 1-cup servings

[b] Recommended during weight loss in the eSDL group only.

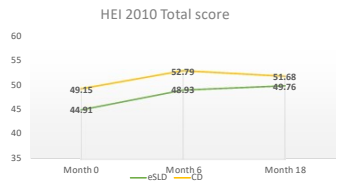
Macronutrient Composition





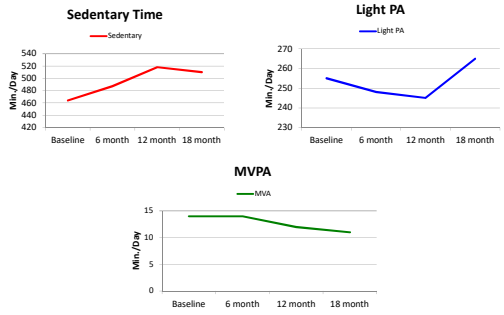


Diet Quality –HEI 2010



- CD no changes in component scores across time
- eSLD increased scores in whole fruits, total vegetables, and sodium.

Physical Activity Changes



Key Points

- We found two different diets that promoted clinically significant changes in health outcomes
  - One diet promoted a faster changes then the other
- Strategies to promote changes in physical activity are still needed
- More cost effective strategies are needed to deliver the intervention

Interested in learning more?

- **Ptomey LT**, Steger FL, Lee J, Sullivan DK, Goetz JR, Honas JJ, Washburn RA, Gibson CA, Donnelly JE. Changes in Energy Intake and Diet Quality during an 18-Month Weight-Management Randomized Controlled Trial in Adults with Intellectual and Developmental Disabilities. J Acad Nutr Diet. 2018 Jan 6. pii: S2212-2672(17)31746-X. doi: 10.1016/j.jand.2017.11.003. [Epub ahead of print] PubMed PMID: 29311038.
- **Ptomey LT,** Willis EA, Lee J, Washburn RA, Gibson CA, Honas JJ, Donnelly JE. The feasibility of using pedometers for self-report of steps and accelerometers for measuring physical activity in adults with intellectual and developmental disabilities across an 18-month intervention. J Intellect Disabil Res. 2017 Aug;61(8):792-801. doi: 10.1111/jir.12392. PubMed PMID: 28707359; PubMed Central PMCID: PMC5546616.
- **Ptomey LT,** Saunders RR, Saunders M, Washburn RA, Mayo MS, Sullivan DK, Gibson CA, Goetz JR, Honas JJ, Willis EA, Danon JC, Krebill R, Donnelly JE. Weight management in adults with intellectual and developmental disabilities: A randomized controlled trial of two dietary approaches. J Appl Res Intellect Disabil. 2018 Jan;31 Suppl 1:82-96. doi: 10.1111/jar.12348. Epub 2017 Mar 23. PubMed PMID: 28332246.
- **Ptomey LT**, Gibson CA, Lee J, Sullivan DK, Washburn RA, Gorczyca AM, Donnelly JE. Caregivers' effect on weight management in adults with intellectual and developmental disabilities. Disabil Health J. 2017 Oct;10(4):542-547. doi: 10.1016/j.dhjo.2017.02.001. Epub 2017 Feb 12. PubMed PMID: 28215627; PubMed Central PMCID: PMC5554465.

Tips for working with individuals with IDD

Mild to Moderate IDD

- Frequent short sessions are best
- Use visuals aids
- Address the individual not the caregiver
- Let the individual be in control of the sessions
- Goals should be realistic and tailored to that person
  - Can't make someone who has an aversions to vegetable start eating 4/day by next session.
- Let the individual set the goals
  - Goals may be different then what you think they should be- but that's okay!
- Make sure they know not to deprive themselves
- Choice is key

Severe IDD

- Assess the living situation
  - Where they live, number of individuals in house, number of caregivers, caregivers load.
- Will most likely need to address the caregiver but still include the individual
- May need to include medical team, depending on living situation
- Small goals
  - Harder to implement if individuals is living in a group environment
- Focus on healthy eating and physical activity first, weight second.
  - Individuals with severe IDD often can't tell you if weight loss is something they want.

A Need for Research

Healthy People 2020

NATIONAL INSTITUTE ON DISABILITY AND REHABILITATION RESEARCH NIDRR

World Health Organization

eat right. Academy of Nutrition and Dietetics

Providing nutrition services for infants, children, and adults with developmental disabilities and special health care needs. J Am Diet Assoc, 2004. **104**(1): p. 97-107.
Hamilton, S., et al., *A review of weight loss interventions for adults with intellectual disabilities.* Obes Rev, 2007. **8**(4): p. 339-45.

HWRN Research Agenda

- **Eating patterns**, eating behaviors, and family practices around food/mealtimes,
- **Physical activity (PA)** and **sedentary behavior patterns** and their relation to weight status
- **The influence of school and community–based organizations** on food intake/PA, and how these environments may be modified to promote healthy weight in youth
- **Prevention or intervention programs and/or systems of care** that can be developed/ adapted/delivered to be responsive to the needs of youth with ASD/DD and yield positive outcomes
- How the **characteristics, experiences, and/or priorities of individuals with ASD/DD and their families** may influence weight status
- **The development and/or assessment of dietary, physical activity, and other relevant obesity-related measures** for use in research with children and youth with ASD/DD

Healthy Weight Research Network | Children with Autism Spectrum Disorder & Developmental Disabilities

HWRN Symposium!

- **Friday April 5, 2019**
- **Omni Parker House, Boston, MA**
  - Presentations
  - Panel Discussions
  - Poster Session
  - Networking
  - And More!
- ***Registration and info coming soon. Check back at http:/HWRN.org in a few weeks***

Thank you!

Questions?

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