Promoting Healthy Habits for Children with Intellectual and Developmental Disabilities

The Let’s Go! Toolkit for Children with I/DD

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Let's Go! is a program of The Barbara Bush Children's Hospital at Maine Medical Center
Objectives

• **Increase** your awareness of the challenges to healthy eating and physical activity faced by children with I/DD.

• **Discover** new strategies, tools, and resources to support healthy habits for children with I/DD.

• **Learn** about the new Health Care Provider Statement Recommending Healthy Habit Goals for children’s education and service plans.
Prevalence of obesity among children with chronic conditions (NSCH 2003)

(Slide, courtesy of Dr. Aviva Must, Tufts University School of Medicine)
Why should we be concerned?

- Increased health problems
- Less Independence
- Higher cost of care
Why is obesity more prevalent among children with I/DD?

• They face the same challenges to being healthy as their peers:
  • Poor nutrition
  • Inadequate exercise
  • Obesity promoting environments

• They also face additional challenges and barriers
Healthy Eating Challenges

- Selective or “choosy” eating (46-89%)
  - Sensitivity to texture, color, smell, temperature, brands of certain foods
  - Unusual and ritualistic eating patterns
  - Preference for energy dense foods
- Disruptive family mealtimes
- Rewarded with preferred food for desired behavior

Raises risk for nutritional deficiencies and/or obesity
Physical Activity Challenges

- Functional Limitations
  - Tire or become over-stimulated
  - Social skill deficits
  - Poor motor skills
  - Mobility challenges
  - Communication differences
  - Need for close supervision or support

- Physical Activities/Programs Not Modified
Barriers to Physical Activity & Physical Activity Levels in Children with Autism Survey Results

Samantha R. White DO PGY3, and Carol L. Hubbard MD PHD MPH. Maine Medical Center; Department of Developmental & Behavioral Pediatrics, Portland, Maine.

November 2015

### Study Participant Demographics

<table>
<thead>
<tr>
<th>Demographic</th>
<th># of Subjects</th>
<th>Average # or % of Group</th>
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</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>84</td>
<td>10.8 years</td>
</tr>
<tr>
<td>BMI (kg/m²)</td>
<td>84</td>
<td>21.2 kg/m²</td>
</tr>
<tr>
<td>Weight (kg)</td>
<td>85</td>
<td>47.4 kg</td>
</tr>
<tr>
<td>Number of meds</td>
<td>85</td>
<td>1.6</td>
</tr>
<tr>
<td>BMI Z-score</td>
<td>84</td>
<td>0.66</td>
</tr>
<tr>
<td>Male</td>
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<td>Female</td>
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<tr>
<td>Asian</td>
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<td>2.4%</td>
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<tr>
<td>Hispanic/Latino</td>
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<td>1.2%</td>
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<tr>
<td>Multiple</td>
<td>1</td>
<td>1.2%</td>
</tr>
<tr>
<td>Sibling without ASD</td>
<td>46</td>
<td>54.1%</td>
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</table>

### Interesting Survey Responses
- Highest Rated Barriers to physical activity:
  - Child’s motivation or interest in being physically active
  - Access to developmentally appropriate programs
- 87% expressed a need for developmentally appropriate programs

### Statistically Significant Findings
- Lower BMI* (z-score)** score was associated with higher activity level
- Child’s motivation was an important factor that was associated with higher activity levels
- In those who had a sibling without autism, the factor most predictive of physical activity was having a sibling without autism

*BMI = body mass index; it is a measure of height & weight together
**Z-score is essentially how far above or below the population average a specific measure is
Impact of psychotropic medication on body mass and growth

For children with I/DD, treating co-morbid issues like anxiety, mood and ADHD can greatly improve functioning, but ----

Some medications can increase appetite and weight
- SSRIs (fluoxetine, esp citalopram)
- Atypical neuroleptics (risperidone, aripiprazole)

Some medications can decrease appetite
- Psychostimulants (methylphenidate, amphetamines), wellbutrin
- May learn unhealthy eating patterns due to efforts to maintain weight and growth

Medications can interfere with eating schedules/timing of hunger
- Can impact meal participation
- Skipping lunch can contribute to irritability
- Getting up to eat at night
The Complex World of a Child with I/DD

Classroom Teacher

PE Teacher

Psychologist

Ed Tech

Social Worker

Behavioral Health Professional

Case Manager

Primary Doctor

Allergist

Endocrinologist

Neurosurgeon

Specialty Care

Cardiologist

Neurologist

Psychiatrist

Special Education Teacher

Occupational Therapist

Physical Therapist

Speech & Language Pathologist

Ther. Rec.

School Nurse

Home

Clinical services and support network for children with I/DD.
Let’s Go! Toolkit for Children with I/DD

- Getting Started
- Healthy Eating
- Non-Food Rewards
- Physical Activity
- Health Care
Healthy Eating Section

Includes:

• When is “Choosy Eating” a problem
• Healthy Foods By Texture
• Tools to Address Eating Problems
• Everyone Plays A Role
“Choosy” Eating

- During the office visit ask about eating habits/feeding behavior.
- Behavior that interferes with a child’s physical or mental health is a concern.
- When concerned, refer for further assessment by BCBA, OT, SLP or other professional.
Helping Children Try New Foods

HEALTHY FOODS BY TEXTURE

Many children with intellectual and developmental disabilities are extra sensitive to the texture of certain foods. This can make it hard for families and caregivers to get them to try new fruits, vegetables, and other healthy foods. Children may be more willing to try new foods if they like how the foods feel. Try introducing children to new foods based on the textures they prefer.

Creamy
- Pureed fruit, such as berries, pears, or apples
- Avocado
- Creamy nut or seed butters
- Cream of wheat
- Yogurt
- Hummus
- Cooked vegetables, such as parsnips or squash
TIP: Puree vegetables together with fruit!

Frozen
- Frozen fruit, like berries, melon, or grapes
- Frozen vegetables, like peas, carrots, and green beans
TIP: You can freeze just about anything! If a child strongly prefers frozen foods, try freezing other foods like cheese sticks and breads.

Crunchy
- Apple varieties like Braeburn, Honey Crisp, Fuji and Gala
- Roasted red or white potatoes (with skins)
- Freeze dried apples and dried mangoes
- Roasted chickpeas
- Roasted vegetables
TIP: Add a sprinkle of bread crumbs for added crispiness!

Crispy
- Veggie sticks, like bell peppers, carrots, jicama, and celery
- Snap peas
- Whole grain cereal with minimal added sugar
- Unsalted nuts
- Whole grain toast or crackers
- Rice cakes
- Plain popcorn
TIP: Add some flavor! Experiment with spices like cinnamon or your favorite spice or herb.
Tools To Address Eating Problems

Includes information on:

- Daily Schedules
- Food Chaining
- Hunger Scales
- Meal Pacing
- Social Stories
- Visual Aids
Everyone Plays A Role

Pediatrician/Psychologist:
- Determine underlying cause of eating problem
- Recommend feeding/healthy eating goals for education and service plans

OT/SPL:
- Help diagnose and treat sensitivities that impact eating

Case Managers:
- Request services that address eating problems
- Ensure goals + strategies are aligned in education and service plans
Selective eating case-AB

History of craniosynostosis (repaired), asthma, delayed language milestones, hypotonia. First seen by DBPeds at age 16 months for concerns about ASD with which he was subsequently diagnosed. Cognition average.

Sensory issues were prominent
- Bathing, sand on his hands, walking on grass, the feel of stuffed animals

Selective Eating
- Objected to the texture of food and perhaps also the color. Ate waffles, string cheese and dry cereal, some pureed foods and yogurt. Recognized the container of a certain brand of yogurt.
- He did not ask to eat, other than breast feeding. At 18 months breastfed 3x daily, ate a few bites of a few foods.

Growth
- Weight started at 90th percentile and his height and weight percentiles gradually dropped. Strong parental concerns about weight loss
Feeding an ongoing concern

18 months: Swallowing study unremarkable. Mother asked for referral to an OT for feeding therapy in addition to speech therapy and private OT for sensory and tone issues.

20 months: Feeding Team evaluation

- Mild to moderate feeding disorder, narrow and inconsistent foods repertoire and intake, adequate oral motor chewing and swallowing skills, Likely not meeting full caloric needs and growth parameters falling off (height and weight were around 3rd percentile). Pediasure recommended.

22 Months: CDS had referred to a nutritionist. Food diaries showed inadequate calories for growth. Mom concerned that eating had not gotten better. Drinking 2 cans of Pediasure daily

Age 3 to 5: Continued OT for feeding at preschool and then kindergarten, small group lunch in OT room. Very limited diet.
Tipping point

Age 6: Weight up to 83rd percentile and height around 20th. BMI 96th percentile

- At DBpeds visit, discussed ways to continue to work to broaden healthier food choices. Started eating apple and grapes. Suggested nutrition referral.
- His mom started working with school staff and OT to substitute healthier snacks and more water.
- Concerns about possible ADHD- diagnosed Dec 2016 and started Adderall

Take home messages:

- Partnership of family, school, providers
- When addressing early selective eating and slow weight gain be careful to recommend healthy foods - may be risk for excessive weight gain and unhealthy eating patterns in the longer term
Non-Food Rewards Section

Why Prohibit Avoid Food Rewards:

- Encourage children to eat outside of mealtimes.
- Add to risk of excessive weight.
- Send a mixed message.
- Foster preference for unhealthy foods
Transitioning to Non-Food Rewards

Increase Your Awareness of the harm of using food rewards

- Learn about non-food alternatives
- Share this knowledge with families
- Talk with the child’s team

Use the Tools in the I/DD Toolkit:

- Food Reward Tracker
- Preference Assessments
- Use Non-Food Rewards
- Use Physical Activity as a Reward
- Transitioning to Non-Food Rewards
- Everyone Plays A Role

Everyone Plays A Role

Special Educators, BCBA

• Conduct preference assessments to identify non-food reinforcers.
• Update the BIP to specify use of non-food reinforcers.

Case Managers

• Ensure non-food rewards/reinforcers are used in child’s ed. and service plans.

Health care providers

• Ask families about food rewards at home and in special education. Discuss the risks.
Physical Activity Section

• Legal requirements

• Tips To Adapt Physical Activities

• Social Inclusion and Physical Activity

• Everyone Plays A Role
Legal Requirements

• PE services, specially designed if necessary, must be available to every child with a disability.

• Specially designed PE – Adapted PE (APE) – provided when there are concerns about whether regular PE is meeting a child’s needs.

• PT and OT may not be substituted for PE or APE.

mainedoenews.net/2016/.../physical-education-requirements-for-children-with-disabilities.
Tips to Adapt Physical Activities

Some examples are:

• Demonstrate activities before you start. Show a video or have another child demonstrate what to do.

• Use Visual Aids such as photo cards to help a child learn a sequence or to make choices.

• Change the rules: let children with I/DD and their peers brainstorm to suggest rules that allow everyone to succeed in a game.

• Review a child’s IEP – understand a child’s “triggers” and address them in advance of an activity.
Social Inclusion and Physical Activity

Help children develop positive social relationships:

• Include social skill development in lesson plans.

• Teach and model social skills in the context where they are needed, such as: recess, PE, after-school.

• Establish a buddy or mentoring system.
Everyone Plays A Role

Health Care Provider:

- Talk to families about importance of PA
- Recommend PA goals for a child’s education + service plans
- Refer for assessment for Adapted PE if appropriate

Special Ed Teachers, BCBA, SLP, OT, PT:

- Determine how to adapt activities and programs to meet a child’s needs
Benefits of exercise

Not just for physical health, but can benefit mood, memory, learning, academics

Effects on serotonin, endorphins, BDNF, neurogenesis, synaptic plasticity

Benefits for children with I/DD include

- Decreased stereotypy, aggression, off-task behavior and elopement
- Improved on-task behavior, academic responding, appropriate motor behavior and peer interaction
Case - MF

MF is a 16 year old male with autism, anxiety and ADHD. In a mostly self-contained classroom setting at school. Seen by DBPeds at age 5, returned age 11 for behavioral concerns- guanfacine started for self-regulation and “anger issues.”

Age 11
- First discussed rapid weight gain- 20 lbs since February
- Nutrigrain bar and milk for breakfast, PBJ and milk for lunch, potato chips, cheese pizza for dinner- had tried veggies and fruit.
- Rec: monitor weight, try to increase physical activity

Age 12 to 13
- Weight continued to climb- gained total of 90 lbs, BMI >95%tile
- Guanfacine and counseling extremely helpful, anger and outbursts much better, “phenomenal’ at school, but concern that guanfacine contributing to weight gain. Working on walking, diet, school sending home food log. Exercise discussed at IEP, running and lifting weights at school.
- Recommended Unified sports, in-home support to encourage exercise
- Sertraline added for anxiety (not leaving house)
Age 13 -14 (8th grade)

- Weight gain continued. His mother was working to change his diet with leaner meats and fewer chips but he was “not impressed.” Eating more veggies.

- Concern that he was winded walking up stairs or even talking. His teacher noted “tires very easily, often has difficulty standing for any time, will ask to sit down or be leaning on something”

- Anxiety prominent, each day a struggle to get him moving, withdrawn, at school disorganized, low-activity level, lots of prompting. Sertraline increased. ADHD diagnosed and dextroamphetamine started

- Private PT started twice weekly for out-toeing and with goal of physical conditioning. Got a treadmill at home. Running and lifting at school. “Boring,” “Too much is too much!”
There is more to the story…

Age 14- 9th grade

- Weight plateaued-peaked at 257 lbs and started to drop
- Working on eating more healthily, eating more different things.
- Exercising at home - sit ups and bike.
- He reported "working hard" in PE at school including jogging in the gym and exercising at home.
- Continued trials of different stimulant medications for ADHD

Spring of 9th grade

- Weight down 14 lbs, endurance better, no longer breathing hard
- Unified basket ball with Lisbon Greyhounds-scored 6 points at recent game
- His mother noted "It is a pretty amazing thing to see- the crowd goes crazy"
Summer after 9th grade

Brought up his weight loss immediately.
- "I try to watch what I eat."
- Often ate salads at school.
- "I drink water every single day- tons and tons."

He continued to work on his physical fitness.
- His SPED class had gym every morning at the beginning of the school day
- Exercising on his own too
- Looked forward to doing Unified Basketball again

Benefits: No longer so winded, falls asleep instantly when he lies down, is ‘coming out of his shyness’ and ‘exudes self-confidence.’

**Take-home messages:** collaboration, referrals, keep discussing healthy lifestyle, encourage sports/extracurriculars, consider role of psychotropic meds
Team sport participation

Cognitively engaging exercise, like sports, has greater effects on the frontal cortex, executive function and memory than repetitive individual exercise.

Higher grades and standardized test scores, complete more years of school, more likely to graduate and also to participate in physical activity in adulthood.

Additional psychosocial benefits over individual exercise:
- Improved self-esteem, social skills, and self-confidence
- Reduced depression, anxiety, and suicidal tendencies.

Barriers for children with DD - intrinsic and extrinsic
WHAT IS UNIFIED SPORTS?

Dedicated to promoting social inclusion through shared sports training and competition experiences, Unified Sports joins people with and without intellectual disabilities on the same team. It was inspired by a simple principle: training together and playing together is a quick path to friendship and understanding.

In Unified Sports, teams are made up of people of similar age and ability, which makes practices more fun and games more challenging and exciting for all. Having sport in common is just one more way that preconceptions and false ideas are swept away.

Our opponent is intolerance. Only shoulder-to-shoulder, as teammates together, can we defeat it.

LEARN HOW YOU CAN BUILD A PROGRAM IN YOUR COMMUNITY

http://www.playunified.org/
A qualitative study of coaches’ experience with players with ASD on secondary school athletic teams

C Hubbard, E Clemetson, K Hyrkas

Themes

• Very positive experience for the coaches
• Climate of acceptance and tolerance set by the coaches
• Coaches tried to treat the PASDs like the other players but did make modifications
• Coaches’ need/willingness to advocate for the PASDs
• Benefit to PASDs- social acceptance and personal growth
• Positive and supportive role of teammates, and beneficial for them as well
Recommend Healthy Habit Goals For Education And Service Plans

“Including goals related to healthy eating and physical activity in a child’s education (IFSP, IEP, Transition Plan) and service plans (Individual Treatment Plan) ensures the child receives appropriate services to meet their needs.”
Health Care Provider Statement Recommending Healthy Habit Goals

Health care providers may use this form to recommend goals related to healthy eating and active living for children. Providers should list suggested goals for school, out-of-school, and/or home settings and give it to the child's parents or caregiver.

Copies of completed forms can also be saved in the patient's chart for future reference.

Patient's Name: ____________________________

Date of Birth: ____________________________

Diagnosis: ____________________________

How the diagnosis impacts the child's health, development, or education:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Suggested Goal/Service/Accommodation at School:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Suggested Goal/Service/Accommodation Outside of School and at Home:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Recommendation for Additional Assessment:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Provider Signature: ____________________________

www.letsgo.org
How to Use the Health Care Provider Statement

1. Identify healthy habit goals with the parent, caregiver and the child/youth.
2. Use the statement to recommend goals, services or assessments.
3. Give the completed statement to the parent /caregiver.
4. Parents/caregivers share the statement with their team at school and/or with their case manager.
5. Parents/caregivers discuss your statement at a team meeting. If approved, your statement can be used to develop special education and service goals that promote healthy habits.

Schools and Medicaid-reimbursed service providers do not have to follow your recommendation but a letter from you can greatly increase the chance of a child getting the goals and services s/he needs.
MAKE REFERRALS FOR SERVICES TO SUPPORT HEALTHY HABITS
for Patients with Intellectual and Developmental Disabilities

Children with intellectual and developmental disabilities (I/DD) often have different needs related to their diagnoses. No single provider is expected to address all of these needs, but a child’s health care provider should become familiar with available services and be able to refer a patient to professionals who can help address challenges. Here are some common challenges and the type of professionals who can help address them.

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<tr>
<th>HEALTHY EATING CHALLENGES</th>
<th>REFERRAL</th>
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<tbody>
<tr>
<td>Sensitivity to food tastes and textures</td>
<td>Occupational Therapist and/or Speech and Language Pathologist</td>
</tr>
<tr>
<td>Highly selective eating</td>
<td>Registered Dietician, Occupational Therapist, and/or Speech and Language Pathologist</td>
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<tr>
<td>Low muscle tone around the mouth</td>
<td>Occupational Therapist and/or Speech and Language Pathologist</td>
</tr>
<tr>
<td>Poor posture that interferes with sitting and with eating</td>
<td>Occupational Therapist</td>
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<tr>
<td>Seeks unhealthy snacks throughout the day</td>
<td>Board Certified Behavior Analyst and/or Psychologist</td>
</tr>
<tr>
<td>Challenging behavior during snack and meal times</td>
<td>Board Certified Behavior Analyst and/or Psychologist</td>
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</table>

<table>
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<tr>
<th>PHYSICAL ACTIVITY CHALLENGES</th>
<th>REFERRAL</th>
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<td>Delayed motor skills impacting activity level</td>
<td>Physical Educator; Adapted Physical Educator; Physical Therapist, and/or Recreational Therapist</td>
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<tr>
<td>Difficulty understanding game rules</td>
<td>Adapted Physical Educator and/or Speech and Language Pathologist</td>
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<tr>
<td>Social skill deficits that prevent involvement in group activity</td>
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<td>Difficulty finding an inclusive after school program</td>
<td>Social Worker</td>
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<td>Tires easily during physical activity</td>
<td>Physical Educator and/or Adapted Physical Educator</td>
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<tr>
<td>Over-stimulated by physical activity</td>
<td>Physical Educator, Adapted Physical Educator, and/or Occupational Therapist</td>
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<tr>
<td>Exaggerated fear of injury during physical activity</td>
<td>Adapted Physical Educator and/or Social Worker</td>
</tr>
<tr>
<td>Not meeting daily recommendation for physical activity</td>
<td>Physical Educator, Adapted Physical Educator, and/or Recreation Therapist</td>
</tr>
</tbody>
</table>
Key Points:

- Be aware of the challenges to healthy eating and physical activity and work as a team to address them.

- Use the **Health Care Provider Statement Recommending Healthy Habit Goals** to recommend physical activity and/or healthy eating goals for special education plans (Individual Family Service Plan, Individual Education Plan, Transition Plan) and/or in-home support plans (Individual Treatment Plan).

- Make a Referral for further assessment when appropriate (e.g. feeding issues, adapted physical education). Remember that PE services must be available to every child with a disability. Adapted PE should be considered when regular PE does not meet a child’s needs.

- Share the IDD Toolkit with families
Consider:

- Read a child’s Individual Family Service Plan, Individual Education Plan and Individual Treatment Plan.

- Provide anticipatory guidance on diet + activity at time of diagnosis of ASD.

- Be aware of how different medications impact appetite and metabolism.
Questions?
Thank you!

The Let’s Go! I/DD Toolkit is available at: www.letsgo.org/toolkits/developmental-disabilities/

For additional questions email me at: dboas@mmc.org