The *Let's Go!* Children with Intellectual and Developmental Disabilities Project: Creating Opportunities for a Healthy Lifestyle

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ABSTRACT

The prevalence of childhood obesity is a growing public health concern. While health professionals have concentrated on finding solutions to obesity in the general pediatric population, there is a lack of understanding of how to promote healthy weight among children with intellectual and developmental disabilities (IDD) in existing obesity prevention programs. In response, *Let's Go!*, a community-based obesity prevention program in Maine, developed a toolkit, trainings, and strategies for increasing healthy eating and active living (HEAL) among children with IDD. In 2016, materials were shared with *Let's Go!* enrolled sites across multiple community and clinical settings.

There was a significant increase in healthcare practices reporting that all providers in the practice recommend HEAL goals for a child's Individual Education Program, from 42% at baseline in 2016 to 73% in 2020. Post-intervention 2017-2020, the vast majority of *Let's Go!* Site Champions at early care and education programs, schools, and out-of-school programs reported that *Let's Go!* tools increased their awareness of challenges to healthy eating and physical activity faced by children with IDD, raised their expectations regarding the capacity of children with IDD to adopt healthy habits, and improved their competency to include children with IDD in their health promotion efforts. The *Let's Go!* approach for addressing obesity in children with IDD is a promising practice and offers the potential for other community-based obesity prevention programs seeking to ensure inclusion of children with IDD.

INTRODUCTION

Obesity among youth with intellectual and developmental disabilities (IDD) is as much of a health concern as it is for typically developing youth. Evidence from nationally representative data suggest that obesity rates among youth aged 10-17 with developmental disabilities including those with intellectual disabilities and autism spectrum disorder are significantly higher than in the general pediatric population. The prevalence of obesity among youth with an intellectual disability (28.9%) is nearly double that of youth without an intellectual disability (15.5%).[1] Obesity among youth with a developmental disability such as autism is 23.5% compared to 15.9% among youth without autism.[2] In Maine, the prevalence of obesity among youth aged 10-17 is 13.2%.[3] Obesity data specific to children with developmental disabilities in Maine are unavailable.

Children with obesity are at risk of both immediate and long-term effects on their health and well-being.[4] Among the already vulnerable population with IDD, obesity substantially increases the risk of several secondary health conditions including asthma, high cholesterol, type 2 diabetes, and depression.[5,6] In addition, obesity among youth with IDD can lead to stigmatization, discrimination, bullying and social isolation.[7]

While health professionals have concentrated on finding solutions to obesity in the general pediatric population, there is a lack of awareness and understanding of how to promote healthy weight among children and adolescents with disabilities.[8-10] A critical need exists to develop inclusion strategies for youth with disabilities in existing community-based obesity prevention programs.[11] Although there is no single or simple solution to reverse the prevalence of obesity, evidence points to changing policies and creating environments that support healthy choices as instrumental in stabilizing and reducing obesity's prevalence.[12] The *Let's Go!* initiative supports such environmental and policy change, and the initiative's strategies and resources can be modified to increase healthy behaviors for children and adolescents with IDD.

LET'S GO! CHILDREN WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES PROJECT DEVELOPMENT

The Let's Go! Obesity Prevention Initiative

Developed in 2004, the Maine Youth Overweight Collaborative (MYOC) was a joint initiative of the Maine–Harvard Prevention Research Center and the Maine Center for Public Health

designed to improve care and outcomes for youth with overweight and obesity. MYOC demonstrated success in the healthcare setting using 5-2-1-0 as a gateway message to guide conversations about healthy habits with patients and families.[13] The 5-2-1-0 mnemonic represents four evidence-based recommendations to follow daily: eat 5 or more servings of fruits and vegetables; limit recreational screen time to 2 hours or less; engage in 1 hour or more of physical activity; and drink 0 sugary beverages.

In 2006, the United Way of Greater Portland convened 6 of the region's prominent healthcare, community, and corporate leaders to launch *Let's Go!*, a community-based approach to improve the underlying health behaviors that have been demonstrated to impact overweight and obesity: healthy eating and physical activity.[14,15] The intervention began as a 5-year, multi-setting demonstration project in 12 municipalities, including Portland, Maine's largest city. The project documented success showing increases from 2007-2011in children's consumption of fruits and vegetables and decreases in sugary drinks.[16] In 2011, *Let's Go!* expanded statewide and transitioned to a program of The Barbara Bush Children's Hospital at Maine Medical Center. Since 2017, *Let's Go!* has partnered with the Maine Center for Disease Control & Prevention (ME CDC) to be the state's primary obesity prevention program. With the ME CDC's help, *Let's Go!* enhanced its programming and more than doubled its capacity across Maine.

Let's Go! is rooted in the social ecological framework of behavior change—that people's behaviors are influenced by many factors including family, friends, local surroundings, the built environment, and community. In order to bring about behavior change, the supporting environments and policies must be changed to make it easier for people to make healthy choices.[17] The *Let's Go!* model involves working with a network of local partners to implement environmental and policy changes that increase opportunities for HEAL in multiple settings, and deploying a consistent message, 5-2-1-0, to encourage children and families to make healthy choices.

Through the partnership of a central *Let's Go!* office and local Dissemination Partners, *Let's Go*! is able to increase its capacity, reach and program sustainability. Dissemination Partners (DPs) are organizations such as hospitals, health systems, public health departments, and community action agencies that share a mission of creating healthier communities. Each DP employs one or more *Let's Go!* Coordinators to work with Site Champions at early care and education programs, schools and out-of-school programs across their communities to create

healthier policies and environments for children and youth. They do this through implementation of 10 strategies that are evidence-based and align with national recommendations to increase HEAL. *Let's Go!* Coordinators deliver trainings and resources to educate Site Champions about the importance of each strategy and how to implement the strategies at their site. In 2011, *Let's Go!* prioritized 5 of the 10 strategies to align with research that indicated they have the greatest impact on HEAL behaviors: (1) limit unhealthy choices for snacks and celebrations and provide healthy choices; (2) limit or eliminate sugary drinks and provide opportunities for water during the day; (3) prohibit the use of food as a reward; (4) provide opportunities for physical activity daily; and (5) limit recreational screen time.

In addition to the environmental and policy change efforts occurring across the community settings explained previously, *Let's Go!* central office staff support healthcare practices by providing trainings and technical assistance around adoption of *Let's Go!*'s clinical strategies. While children make healthy choices in early care and education programs, schools, and out-of-school programs, the importance of 5-2-1-0 is reinforced when they visit their healthcare provider. Displaying the *Let's Go!* 5-2-1-0 poster in the clinical setting is a simple, yet important step because it reinforces a message that children and their families encounter in other places in their community. In addition, healthcare providers use the 5-2-1-0 Healthy Habits Questionnaire with pediatric patients to initiate respectful conversations around HEAL. With these clinical strategies, providers are fulfilling a crucial role in *Let's Go!*'s multi-setting approach.

Development and evaluation of the *Let's Go!* Children with Intellectual and Developmental Disabilities Project is described in subsequent sections. The goal of the project was to create an inclusive program that would increase awareness of the challenges of HEAL for children with IDD, and raise expectations regarding the potential and right of children with IDD to be healthy.

Why Adapt Let's Go! for Children with Intellectual and Developmental Disabilities

Current obesity prevention strategies and interventions for typically developing children may not be appropriate for children with IDD.[5,10,18] Researchers emphasize the need to adapt existing programs "such as tailoring to enhance their accessibility, relativity and inclusivity" and to take a comprehensive approach that addresses multiple risk factors including diet,

physical activity, medications, and screen time usage.[6,10] Findings from a survey with pediatricians show that while most pediatricians believe they are responsible for managing obesity in children with IDD, few feel they have adequate training to do so.[19] Together, these studies indicated that *Let's Go!*'s model for behavior change could be adapted to include children with IDD. The model targets multiple risk factors through its five priority strategies and takes a comprehensive approach through consistent messaging across different settings. In addition, *Let's Go!* could build on 16 years of experience training clinicians on obesity prevention for typically developing children to address the needs of more complex pediatric patients. A description of the process for adapting the *Let's Go!* model follows.

Let's Go! Children with Intellectual and Developmental Disabilities Project

One of the guiding principles of *Let's Go*! is the belief that all children deserve equal opportunities to lead healthy lives. In 2016, *Let's Go!* received funding to develop the tools, strategies and resources to put that belief into practice. The *Let's Go!* Children with Intellectual and Developmental Disabilities Project has 3 key objectives: (1) increase awareness of the challenges to healthy eating and physical activity faced by children with IDD and their capacity to lead healthy lives; (2) raise expectations regarding the potential and right of children with IDD to be healthy; and (3) adapt *Let's Go!* messages and strategies to ensure that enrolled early care and education programs, schools, out-of-school programs, and healthcare practices have the tools and resources to include children with IDD in their obesity prevention efforts.

Increase Awareness of Health Challenges and Opportunities for Children with IDD

Educators, healthcare providers, families, and other stakeholders cannot collectively improve the health of children with IDD without an understanding of obesity, the risks it poses, and the specific challenges to maintaining a healthy weight faced by this population. *Let's Go!* developed the *Let's Go!* Toolkit for Children with Intellectual and Developmental Disabilities to help increase awareness and understanding of these issues. Publicly available on the *Let's Go!* website, this toolkit contains new and adapted tools, strategies, and resources that complement *Let's Go!*'s core 5-2-1-0 message and strategies while addressing the specific needs of children with IDD. For example, a new resource organizes healthy snacks by texture to help caregivers introduce new foods to children with selective eating habits. Resources were

created to increase children's participation in physical activity including tips on how to modify activities and ways to address social skill deficits during play. The healthcare section of the IDD toolkit emphasizes that *Let's Go!'s* clinical strategies apply to all children. New strategies and messages for healthcare providers were developed to increase their understanding of the needs of children with IDD.

Awareness of the challenges facing children with IDD was also fostered through a suite of professional development activities including in-person trainings, webinars, and technical support. To ensure ongoing sustainability, the IDD tools, strategies, and resources are integrated into *Let's Go!*'s master training slides, ensuring that all training participants increase their awareness and understanding of how to include children with IDD in their obesity prevention efforts. *Let's Go!* staff and partners use the slides to support implementation of recommended strategies at over 1,500 enrolled sites.

Let's Go! updated its marketing and communication plan to incorporate inclusive messages and expanded its image library to include children with IDD engaged in healthy behaviors. These messages and images are included in all new collateral materials. *Let's Go!* also promoted the IDD tools on social media. An announcement about its release with a link to the toolkit on the program website was shared with the American Academy of Pediatrics and other leading national and state education, healthcare, and disability-related organizations.

Raise Expectations about Healthy Behaviors of Children with IDD

Early care and education programs, schools, out-of-school programs, and healthcare practices should offer children with IDD the same opportunities to eat healthy and be active as their typically developing peers in order to help them lead long, healthy and rewarding lives. *Let's Go!* engaged stakeholders in the development of tools and key messages by inviting professionals with an interest in the health of children with IDD to serve on the project's Advisory Committee. Advisors included *Let's Go!*'s senior director, who is also a pediatrician, a developmental-behavioral pediatrician, a psychologist, a community service provider, the executive director of the Maine Chapter of the American Academy of Pediatrics, public health administrators from the Maine Center for Disease Control and Prevention and the Department of Health and Human Services, and parents of children with IDD.

Let's Go! educated healthcare providers about the importance of including children with IDD in their obesity prevention efforts through professional development opportunities including webinars, lunch-and-learn events, and a Grand Rounds at The Barbara Bush Children's Hospital at Maine Medical Center. *Let's Go!* also developed an online video for healthcare providers that describes how to help their patients with IDD address challenges adopting healthy habits.

Adapt Let's Go! Messages and Strategies for Children with IDD

Let's Go! developed messages emphasizing collaboration among the multiple providers and caregivers who work with children with IDD in different settings. Increased collaboration helps support implementation of the strategies promoting HEAL wherever children live, learn and play, which is consistent with *Let's Go!*'s overarching philosophy. *Let's Go!* adapted 3 of its 5 priority strategies for the IDD Toolkit: (1) limit unhealthy choices for snacks and celebrations; provide healthy choices; (2) prohibit the use of food as a reward; and (3) provide opportunities for physical activity daily. Strategies (1) and (3) were selected based on research underscoring their impact on overweight and obesity. Strategy (2) was chosen in response to *Let's Go!* partners who requested help aligning this strategy with the use of edible reinforcers in special education.

Community service professionals who provide Medicaid-funded services such as case management and in-home support, do not receive adequate training on how to promote healthy habits for children under their care. *Let's Go!* adapted its messages and strategies as part of a new training to increase the competency of these professionals. *Let's Go!* piloted this training to social service agencies working in southern and central Maine.

The healthcare section of the toolkit contains new messages and strategies for providers based on recommendations made by the Centers for Disease Control and Prevention and the American Academy of Pediatrics. Healthcare providers are encouraged to increase their understanding of special education in schools and to recommend HEAL goals for a child's Individual Education Program (IEP). To facilitate healthcare providers' involvement in the IEP process, *Let's Go!* created a form that healthcare providers can use to recommend goals, services, accommodations, or assessments. The provider can complete the form during the office visit and give it to the family for them to share at team meetings.

EVALUATION OF THE PROJECT

Evaluation Groups

Let's Go! evaluated project outcomes by conducting surveys with 2 different population groups. The first, Group A, are *Let's Go!* Site Champions in the early care and education, school, out-of-school, and healthcare settings. Site Champions complete annual surveys that enable *Let's Go!* to track site-level implementation of strategies for increasing HEAL. Site Champions in these settings include classroom teachers, school nurses, physical education teachers, health teachers, guidance counselors, program directors, health and nutrition coordinators, RNs, physicians, medical assistants, and office managers. The second population, Group B, are people who attend *Let's Go!* IDD-focused trainings. Training attendees provide feedback to *Let's Go!* in post-training surveys. The IDD-focused trainings are offered to professionals who work with children with IDD including behavioral health professionals, case managers, special educators, physicians and other medical staff.

Measures

Surveys were conducted annually by setting with population Group A. In the healthcare setting, web-based surveys were emailed to practices to track implementation of *Let's Go!* clinical strategies. Practice managers were asked to complete the survey with input from medical staff in their practices. Beginning at baseline in 2016 prior to the intervention, items were added to the annual survey to assess implementation of clinical strategies for patients with IDD. Two questions were tracked each year for this evaluation: (1) "At well-visits, how many providers in your practice routinely counsel their patients with IDD on healthy eating and active living using the 5-2-1-0 Healthy Habits Questionnaire?" and (2) "At well visits, how many providers in your practice routinely recommend that eating/nutrition goals and physical activity goals are included in a child's Individual Education Program (IEP)?"

In the early care and education, school, and out-of-school settings, web-based surveys were emailed to enrolled sites to track implementation of *Let's Go!*'s 10 strategies. Each year post-intervention, 3 items were added to the surveys to track: (1) if the Site Champion had used the *Let's Go!* IDD toolkit, and if so, their level of agreement on a 4-point scale with 2 statements: (2) "The *Let's Go!* IDD tools have increased my awareness of the challenges to healthy eating and physical activity faced by children with IDD," and (3) "The *Let's Go!* tools increased my

expectation that children with IDD have the capacity to eat healthy and be physically active." In 2018, a fourth question was added to the school survey that asked if the district has a physical education teacher with Adaptive Physical Education (APE) certification.

A survey also was developed for attendees of IDD-focused trainings, population Group B. *Let's Go!* facilitated 62 trainings between October 2016 and April 2019 attended by 970 people. The trainings focused on evidence-based practices for addressing the unique needs of children with IDD regarding HEAL. The post-training survey instrument included items that measured respondents' level of agreement on a 4-point scale that the training effectively addressed the objectives, met their expectations, was well organized, and that they gained knowledge and skills that they can apply to their *Let's Go!* work. Other items included a 5-point scale to rate the training from "very poor" to "excellent," and a 4-point scale to learn if they would recommend the training to others from "no, definitely not" to "yes, definitely." All analyses were performed using IBM SPSS Statistics version 26.

Evaluation Findings

Annual Surveys

There was a statistically significant increase in the percentage of healthcare practices reporting that all providers in the practice met the strategy to recommend healthy eating and physical activity goals for a child's IEP, from 42% at baseline in 2016 to 73% in 2020. There was a slight increase, though not significant, in practices reporting that all providers use the 5-2-1-0 Healthy Habits Questionnaire with their patients with IDD to counsel on healthy eating and active living, from 75% in 2016 to 81% in 2020 (Table 1).

In the early care and education, school, and out-of-school settings, among respondents who used the IDD toolkit, the vast majority of *Let's Go!* champions reported annually that the *Let's Go!* IDD tools increased their awareness of the challenges to healthy eating and physical activity faced by children with IDD, and increased their expectations that children with IDD have the capacity to eat healthy and be physically active (Table 2). In addition, 34% of school champions in 2018, 36% in 2019, and 36% in 2020 said their district has a physical education teacher with Adaptive Physical Education (APE) certification.

Table 1. Percentage of *Let's Go!* Healthcare Practices that Met the Strategy

	2016 (baseline)	2017	2018	2019	2020
			n		
	152	139	131	128	104
At well-child visits, all providers routinely counsel patients with IDD on healthy eating and active living using the 5-2-1-0 Healthy Habits Questionnaire.	75%	74%	79%	80%	81%
At well-child visits, all providers routinely recommend that healthy eating/nutrition goals and physical activity goals are included in a child's Individual Education Program.* † **	42%	45%	54%	59%	73%

Note. Change was considered significant when $p < .05$: * = 2016 to 2018, † = 2016 to 2019, **2019-2020.

Table 2. Percentage of *Let's Go!* Site Champions Who Agree or Strongly Agree with Statement

Post-Intervention	School Champions				Early Care and Education Champions				Out-of-School Champions			
	2017	2018	2019	2020	2017	2018	2019	2020	2017	2018	2019	2020
	n				n				n			
	65	86	120	132	115	177	229	234	37	37	43	49
The *Let's Go!* IDD tools have increased my awareness of the challenges to healthy eating and physical activity faced by children with IDD.	91%	97%	95%	100%	94%	92%	95%	97%	92%	89%	95%	100%
The *Let's Go!* IDD tools have increased my expectation that children with IDD have the capacity to eat healthy and be physically active.	92%	97%	95%	100%	92%	93%	95%	96%	97%	89%	84%	100%

Trainings

For population Group B, in post-training surveys among 188 respondents, 86% said the training effectively met the training objectives, 78% said the training met their expectations, 79% said the content of the training was relevant to their *Let's Go!* work, 80% said they will be able to use what they learned in the training, and 91% said they would recommend the training to others.

DISCUSSION

The *Let's Go!* Children with Intellectual and Developmental Disabilities Project met its 3 key objectives: (1) increase awareness of the challenges to healthy eating and physical activity faced by children with IDD and their capacity to lead healthy lives; (2) raise expectations regarding the potential and right of children with IDD to be healthy; and (3) adapt *Let's Go!* messages and strategies to ensure that enrolled early care and education programs, schools, out-of-school programs, and healthcare practices have the tools and resources to include children with IDD in their obesity prevention efforts. The project met these objectives through the development and dissemination of the IDD Toolkit and delivery of trainings customized for specific groups of professionals.

Results from the IDD focused post-training surveys demonstrate that trainees gained knowledge and skills empowering them to promote their *Let's Go!* work with children with IDD. *Let's Go!*'s annual survey results reveal that usage of the toolkit was an effective way to meet the project's objectives. In the school setting, the slight increase among the number of school champions who report their district has a physical education teacher with APE certification is promising, as students with IDD are less likely to participate in school-based physical activities unless those activities are adapted for them.[11] The American Academy of Pediatrics recommends that primary care physicians increase their involvement in the IEP process by recommending goals that support healthy behaviors.[20,21] It is informative that surveys from the healthcare setting demonstrate a statistically significant increase in providers recommending those goals. Giving healthcare providers tools for helping children with IDD adopt healthy eating habits and increase their level of physical activity, is particularly important as research indicates that parents of children with autism who have obesity are more concerned than parents of typically developing children about their child's weight status.[22] Moreover, parents often feel their healthcare providers do not understand the challenges they face trying to

improve their child's diet and physical activity and therefore are less likely to follow their provider's advice.[23]

This project had some challenges. While there was interest, there were systemic barriers that sometimes made it more difficult for professionals to use the *Let's Go!* strategies, tools and resources to promote healthy habits. Some physicians felt they did not have adequate time to discuss individual challenges to HEAL faced by patients with IDD. They have few professionals to collaborate with as recommended, specifically those with experience treating selective eating habits. Within schools, there is a lack of certified adapted physical education teachers and over use of edible reinforcement continues. Moreover, community service providers are often unable to implement strategies and sustain efforts due to workforce shortages and high turnover rates.

CONCLUSION

Children with IDD are growing up alongside their typically developing peers and deserve the same opportunities to participate and benefit from health promoting activities offered in their schools and community programs. Despite recommendations by Healthy People 2020 and growing demand for inclusive community-based obesity promotion programs that meet the needs of children with disabilities, few have been developed. To our knowledge, *Let's Go!*'s Children with Intellectual and Developmental Disabilities Project is one of the few examples. The toolkit, the trainings adapted to include IDD information, and the more inclusive marketing campaign all served to increase awareness of the challenges of HEAL for children with IDD, and raise expectations regarding the potential and right of children with IDD to be healthy. The findings from both the post-training surveys and *Let's Go!*'s annual surveys with Site Champions reinforce the importance of giving professionals evidence-based strategies and resources for them to effectively include children with IDD in their obesity prevention work.

Let's Go!'s inclusive obesity prevention model addresses the critical need for programing that can reduce the obesity risk for children with IDD. Consideration of children with IDD is now woven into all aspects of *Let's Go!* from strategic planning through professional development, marketing and evaluation. The *Let's Go!* Children with Intellectual and Developmental Disabilities Project successfully increased awareness of the challenges to healthy eating and physical activity faced by children with IDD, and raised expectations regarding the potential and right of children with IDD to be healthy. The *Let's Go!* approach for addressing

obesity in children with IDD is a promising practice and offers the opportunity for other community-based obesity prevention programs seeking to ensure inclusion of children with IDD. Additionally, it is hoped that programs like *Let's Go!* will reduce health disparities in this population by helping to institute policies that ensure all children have access to healthy food and active living.

Other programs interested in promoting healthy weight among children with IDD can follow the steps as described in this paper and broadly outlined below.

- Convene an Advisory Committee comprised of stakeholders with experience and interest in improving health outcomes for children with IDD.
- Review current strategies used to promote HEAL for typically developing children and modify them to help children with IDD compensate or overcome challenges they would face without these modifications in place. Consider that strategies need to reflect specific settings and the needs of a targeted age group.
- Create professional development activities that include educational materials and trainings for each setting (e.g. healthcare practices, early care and education programs, and schools).
- Evaluate and modify as needed.

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