

The Diabetes Prevention Program: Recommendations for increasing accessibility for people with intellectual and developmental disabilities

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Statement of the Problem

People with intellectual and developmental disabilities (I/DD) are more overweight and less active than the general population. They also experience higher rates of secondary conditions associated with obesity and inactivity, such as type 2 diabetes, heart disease and other metabolic conditions. This health disparity is due to several factors including physical and cognitive limitations, medications, lack of accessible fitness facilities and developmentally appropriate and inclusive community programs. Health promotion programs that include diet, exercise and behavior modification can promote successful weight loss and reduce or prevent the chronic complications of obesity. Unfortunately, few health promotion programs target adults with I/DD. Therefore, there has not been extensive research on health promotion programs and outcomes for people with I/DD. Researchers recognize the considerable barriers to collecting valid data, and have not yet validated a method for dietary assessment for adults with intellectual and developmental disabilities (Ptomey, et al, 2013). However, there is evidence that persons with I/DD do care about their health. They can be recruited into a diet and physical activity programs, and be successful with the appropriate interventions and support systems in place (Saunders, et al, 2011).

The Diabetes Prevention Program (DPP) is a CDC-recognized diabetes prevention lifestyle change program to help prevent or delay type 2 diabetes. Research by the National Institutes of Health and the Centers for Disease Control and Prevention found that participants who lost a modest amount of weight through dietary changes and increased physical activity sharply reduced their chances of developing diabetes. The DPP was designed and found to be an effective health promotion training for adult learners with typical learning abilities. This paper identifies and describes potential strategies that can be used to the DPP to enhance the learning experience for people with I/DD.

MI-DDI worked in partnership with the National Kidney Foundation of Michigan (NKFM) to identify barriers to delivering the DPP to individuals with I/DD and strategies for

overcoming these obstacles. The NKFM has extensive experience delivering the DPP to people with and without I/DD. The NKFM project team members identified several strategies for improving accessibility which are described in detail below. MI-DDI also conducted a comprehensive review of the literature related to support these recommendations.

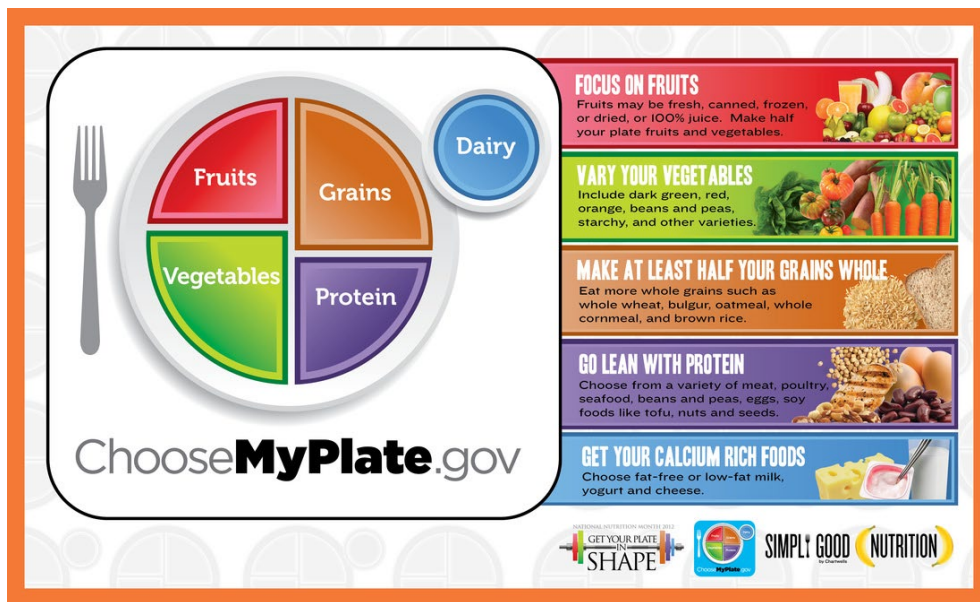
Recommendations to Increase DPP Accessibility

Recommendation #1: Simplify tracking tools

As with most participants in a weight loss or exercise program, tracking daily behaviors is necessary to monitor progress. People with I/DD are no different than other people participating in health promotion programs; tracking dietary and exercise activities is challenging and cumbersome. It takes time, practice, vigilance and accuracy to be effective. There is also a reliance on literacy, numeracy and writing skills to document dietary or physical activity. Documentation must be done daily at minimum and many health promotion programs require participants give their documentation to the program facilitator so progress can be monitored, recorded and documented. Tracking helps people identify healthy and unhealthy food choices, and can help direct them towards wise choices. As indicated in the literature review, people with I/DD may not have the literacy skills or ability to track their food and exercise by traditional options, or they may need supplemental tools to make their tracking successful.

The DPP expects participants will lose 7% of their body weight and participate in 150 minutes of physical activity at the conclusion of the 16-week class. Vigilant and accurate diet and exercise documentation are needed in order for the DPP to be considered successful. Tracking has other benefits as well. The DPP gives participants a tracking form, to record their daily food intake. The tracking table, gives participants space to write what they ate and the quantity for each meal or snack consumed. The documentation requires reading and writing levels to be at least at a grade six level. And for that reason, many people with I/DD would not be able to complete the form independently. The literature identified more simplistic ways of dietary and activity tracking. One example is (Saunders et al, 2011), forms for self-recording energy intake and outputs by using seven columns of icons, one column for each day of the week. Each icon was represented by fruit, vegetables, entrees, snacks and exercise. Simple symbols were used instead of words to assist in the documentation process. For example, a carrot represented vegetables, two apples represented fruit a tennis shoe recognized an exercise activity,

and next to the food entries participants were instructed to put a red, yellow or green dot depending on what they ate. This tracker, kept the description of the food and exercise minimal, and made the tracking a simpler process for people with I/DD. In the (Saunders et al, 2011) study family or direct care workers filled in the dietary and exercise tracker, for people who could not complete the process alone.



Recommendation #2: Tracking with Photo Assisted Recall

Photo assisted food recall is a technique using digital images to record food intake. While there is limited research on the topic, (Elinder, et al, 2012, Humphries, et al, 2008) findings suggest that photo-assisted recall can improve the measurement of total energy and macronutrient intake for individuals with I/DD. A study (Ptomy, et al, 2013) of adults with I/DD (n=23; ages 23-60 years of age), used iPad cameras to record daily food intake in addition to the standard recall method. The aim of the study was to determine if photographing food significantly improves the estimated amount of energy and macronutrient intake reported in 24 hour dietary recalls for people with I/DD. To record the photos all participants received an iPad 2 (Apple) Wi-Fi model, and participants and caregivers received training in how to operate the tablet. Calendar prompts were programmed into the tablet to remind participants to comply with the photo protocol. A home visit by a Registered Dietician (RD) provided individual assistance with the standard recall and provided educational information and hands on tools to encourage

accurate recall by the participants. The tools included, three dimensional food models, glasses, dishes, mugs and bowls, geometric shapes simulating food portions and plastic food items. The portion guides used in the home visit were three dimensional models of food to be used as a reference to improve recall accuracy. A grid wedge was provided and was to be placed next to the plate of food being photographed, to assist the RD in estimating the serving sizes. The RD reviewed each photo, for food content, portion size and any other details about any food items that were different from the standard recall. Additional details, including why there was a difference between the photograph and what was on the standard dietary recall form were noted by the RD. The RD entered all the dietary records into the Nutrition Data System for Research software. All photos were also entered into the Nutrition Data System for Research software to determine intake of total calories, grams of fat, carbohydrates and protein. Models of analysis were adjusted to accommodate for varying levels of participant's intellectual capacity. The results of this study indicated that the use of photographs in tracking 24 recall of food, provides significantly greater intake of total calories and macronutrients compared with standard 24-hour food recalls. These results suggest that utilization of the standard 24-hour tracking methods alone can underestimate dietary intake in adults with I/DD. This finding are consistent with the learning retention and memory recall challenges people with I/DD experience. The range of age in the participants also suggests younger and older people are able to learn to use cameras to assist in dietary recall. This study also concluded that more food was recorded when using photographs versus standard recall because people forget what they eat and or have difficulty documenting what they ate. Pictures objectively show food and food portions, and this is another reason why photographing food is a more accurate account of what is consumed. This study provides evidence that taking photos of food intake, may be a feasible dietary assessment method in adults w/ I/DD, that can improve estimates of dietary intake and lead to healthier life choices Unfortunately, there are financial issues to consider when promoting this as an intervention, because of the costs of the Smart Phones and IPads needed to take the photographs. The NKFM project staff have also shared concern about the limited availability of this technology to people with I/DD. Certainly this is a barrier for some individuals, who do not have access to photo assisted technology and this is a limitation of this intervention.

Recommendation #3: Stop Light Diet (SLD)

Originally designed to be used with children and adolescents, the Stop Light Diet is a simple means to identify and distinguish foods that are low in calories and nutritious and foods that are sometime treats because they are high in calories and low in nutrition. The Stop Light Diet (SLD) has been evaluated by the Academy of Nutrition and Dietetics Evidence Analysis Library and found to be an effective weight loss strategy for children. The SLD categorizes foods with three colors: green (low energy: consume freely), yellow (moderate energy: consume in moderation) and red (high energy: consume sparingly). Foods that are 60 calories or less are coded with a green dot, foods between 60 and 100 calories are coded with a yellow dot and foods that over 100 calories are coded with a red dot. Using either the visual aid or the written form participants can refer to the Stop Light guide while preparing menus, shopping lists and before they eat a meal or a snack. Stop Light can be used as a quick reference guide to help individuals make a healthy food choice, before eating and to guide their choices to the most nutritional food. Stop Light is easy for people with I/DD and their caregivers to understand and adopt (Donnelly, et al, 2013) and requires little reading and reading comprehension skills.



Recommendation #4: Pre-prepared Packaged Meals

The University of Kansas Weight Loss Project, is a twelve-month weight loss and exercise health promotion program for adults with I/DD. On this diet participants replaced their typical breakfast meal with a smoothie shake. At lunch and dinner, they could choose from a variety of pre-prepared entrées that were high in protein and low in carbohydrates. The participants could eat as many fruits and vegetables as they desired each day. Desserts were only to be consumed on rare occasions. When participants wanted to snack between meals, health bars, or fruit was the encouraged choice. The Stop Light diet was taught and used by participants, to encourage healthy low calorie food choices. The success of the weight loss program was credited to several variables, and included the ease of using pre-packaged meals as an alternative to preparing, cooking and cleaning up after a traditional meal. Interviews with participants indicated that offering pre-packaged meal options, limited undesirable meal choices, taught appropriate portion sizes and were convenient to prepare. Participants paired the prepackaged meals with high volume foods, and this reduced between meal hunger (Donnelly, et al, 2009). There is strong evidence in the literature that effective self- monitoring and meal replacements and/or pre-planned structured meal plans are strategies that facilitate health and food behavior changes in the general population (Spahn, et al, 2010). The (Saunders, et al, 2011; Donnelly, et al, 2013) articles prognosticate that prepackaged meals may be an important component to teaching and supporting healthy lifestyle habits in adults with I/DD as well. The average weight loss for the 75 individuals completing the diet phase was 13 pounds or approximately 6% of their baseline weight. The researchers noted that this weight loss mirrored the DPP expected group weight loss fairly closely. The adults participating in this program lived in all types of residences, and not surprisingly those that lived in their own homes or apartments lost the most weight (18 pounds) while people living with a spouse or large group home lost the least. However, these weight loss results are from a small sample size and may not be validated when the intervention is applied to a larger sample size.

Recommendation #5: Pedometers and Activity Trackers

The University of Kansas Weight Loss program for adults with I/DD provided participants with pedometers to track the number of steps they took each day. The researchers developed and provided individuals with a colorful game board, that had a path of 10,000 steps that were boldly marked on the game board, leading to the grand finale: 1,000,000 steps. Each person received a game board, and tracked their activity progress towards the grand finale. For each 100,000 steps documented on the game board they received five dollars as an incentive. Participants were encouraged to wear the pedometer and to write down their count on a tracking form, each day, then mark progress on the game board. The physical exercise goal was to complete 150 minutes per week. Other forms of physical exercise were encouraged and counted towards the weekly 150-minute requirement. In addition to money other incentives used in this program included award certificates, stickers, bragging cards and high-fives from the group.

Tracking physical activity is an important part of changing sedentary patterns of behavior. An individual can see their progress and also identify barriers that impede them from participating in physical activities. The literature suggests that all people wanting to promote an active lifestyle, can benefit from monitoring their progress. Pedometers, are a low cost effective monitoring tool, that could be effective for people who have I/DD. Perhaps, coupled with a reward system, or a small monetary award, the use of pedometers could be implemented into the lifestyles of people with I/DD to influence them to increase their physical activity.

Recommendation #6: Engage Peer Mentors, Direct Support Staff and Family

The Diabetes Prevention Program Research Group credited several factors for the successful outcomes participants attain when participating in a Diabetes Prevention Program. Individual lifestyle coaches were ranked first on their list of eight factors. The literature affirms that there is a compelling case to promote the use of peer mentors in any program aimed at teaching and changing behaviors, whether an individual has a disability or not. Caregivers play an important role in the life of a person with I/DD. It is often the case that caregivers and direct support staff purchase and prepare food for the individuals they support. A direct care worker

and or family member that provides the meals to an individual with I/DD would be an ideal recruit as a peer mentor in health promotion activities (Donnelly, et al, 2009).

The Kansas University Weight Loss Project, called direct support staff and family members “Study Partners”. The researchers directing the project noted that many of the direct care staff and family study partners were also overweight and making poor nutritional and life style choices. The Study Partners had to agree to support the participant in their weight loss program and to encourage and promote healthy food and exercise choices using nonjudgmental language. Study Partners received training on how to use Stop Light, healthy nutrition options, how to plan healthy menus, grocery shopping, and meal preparation. They also received training on how to help participants make healthy choices that prompted corrective action without using negative words while promoting individual self-determination and choice making. Study Partners assisted some participants in the data recording methods, to follow accurate tracking and progress. The participants that lost the most weight, also had someone in their circle of support i.e. Study Partner, or family member that was also invested in the weight loss program.

The Healthy Lifestyle Change Program, hired and trained peer mentors that had developmental disabilities believing peers were better equipped than professionals to support others who face similar challenges and barriers to health (Bazzano, et al, 2009). Peer mentors received training on the health and fitness program, leadership, and motivational strategies, to prepare them to become teachers and role models. They made reminder phone calls to participants, led physical activity sessions, prepared healthy snacks for the meetings and helped facilitate review sessions. The Healthy Lifestyle Change Program participants median weight loss was 7 lbs. (range:2-24 lbs.), and Body Mass Index (BMI) as well as abdominal girth decreased in 74% of the 44 participants completing the seven-month program. Additionally, physical activity increased in 61% of the participants. The researchers concluded that community based health promotion and education programs should use peer mentors to increase the successful completion of these programs for people with I/DD.

Recruiting People with Intellectual and Developmental Disabilities for the DPP

Currently, very few people with I/DD participate in the Diabetes Prevention Program (DPP). This is unfortunate because it is estimated that the prevalence of obesity is 2.1 times higher for individuals with I/DD when compared with the general population (Saunders, et

al., 2011). The association between obesity and type 2 diabetes is strong, and approximately 80% of type 2 diabetics are overweight. The DPP could benefit this population, but there are challenges in getting people with I/DD to participate, in addition to the complexities of the curriculum. These challenges, are cited in the literature and include, transportation, access to community programs, lack of control over daily choices, and limited knowledge about the benefits of participating in health promotion activities. However, there are recruitment options that may reduce some of these barriers resulting in more people with I/DD participating in the program. These recruitment strategies are intended to promote community inclusion, peer relationships, increase self-efficacy and healthier lifestyles for people with I/DD.

Recommendation #1: Service Providers

There are agencies that provide services to people with I/DD and they may be a conduit between the DPP and people with I/DD. Identifying these agencies and facilitating a discussion between them and NKFM may result in people with I/DD, their family and direct care workers obtaining DPP information through the agency's website. There could also be a link that takes people to the statewide DPP website that lists the location and times meetings are convened statewide.

Recommendation #2: Home Providers

People with I/DD often live in group homes or in semi-independent living situations, that are operated by home provider agencies. The Michigan Assistance Living Association (MALA) is an organization that represents many statewide home provider agencies and would be a way to identify contacts to share information about the DPP. Home provider administrators, that understand the benefits of having employees that participate in the DPP may then promote attendance for home managers, direct care staff and people with disabilities. There is evidence that when people have a peer or buddy, to participate in a health promotion activity with them, they tend to both achieve better and longer lasting results from participation. For people with I/DD having direct support staff attend DPP has other benefits too, including having transportation to the class and direct support staff that understand the importance of healthy lifestyle choices. In a group home it is often the direct care workers that plan the menus, shop for the food, and prepare the meals. Having a direct care worker that attends the DPP with the person with I/DD may result in healthier meals as well as an activity that promotes a partnership

that both parties benefit from long term. People with I/DD attending DPP at a local venue also promotes an age appropriate activity in an inclusive environment.





















































Recommendation #3: Self Advocacy Networks

The Self Advocates of Michigan (SAM) is a self-advocacy network sponsored by the Michigan Developmental Disabilities Council. Contacting SAM and providing the group with information about the DPP, may be a way to encourage participation for people with I/DD. A DPP webinar highlighting the benefits of participation could be sponsored for SAM members. Webinars are an effective educational platform that is low cost to produce and provides easy access for participants. Webinars can be archived and watched multiple times, which may be helpful for people with learning challenges and low literacy.

Conclusion

The recommendations in this paper highlight interventions from the literature and input from the National Kidney Foundation of Michigan project team. These strategies are intended to increase the accessibility of the Diabetes Prevention Program for people who have I/DD. It is important to keep in mind that the DPP curriculum was carefully field tested so caution must be exercised when considering modifications to this evidence based curriculum. Changes to the curriculum content could inadvertently negatively impact its validity and could result in less effective outcomes for people with and without disabilities. The proposed recommendations are intended to supplement the DPP curriculum and should be evaluated for effectiveness in improving outcomes for people with I/DD as well as improved access and inclusion in DPP offered in the community.








































The University of Kansas Diet Project Diet Record

Name:		Diet Record				Week #	
MON		TUE		WED		THURS	
food eaten		food eaten		food eaten		food eaten	
							
							
							
							
							
							
							
							
							
							
							
							
steps: _____ 	steps: _____ 	steps: _____ 	steps: _____ 				
exercise type: _____ total exercise minutes: _____	exercise type: _____ total exercise minutes: _____	exercise type: _____ total exercise minutes: _____	exercise type: _____ total exercise minutes: _____				








DIRECTIONS: The food items above the 1st blue dotted line represent the recommended foods to consume daily. Circle the pictures of the food items that you eat each day. If you eat more food items than there are icons to circle, please indicate the extra items next to one of the pictures (i.e. write x2 for 2 items consumed). You may also list what you ate next to the picture if you wish. Circle the shoe if you did planned exercise for at least 10 minutes consecutively. Also, list the type of exercise(s) you did and list the total exercise minutes you did that day. For example: exercise type: treadmill & elliptical, total exercise minutes: 30 min. Walking around the block for at least 10 minutes would count but walking at work in order to accomplish your job would not count. If you are using a pedometer, record your daily steps before bed each night next to the shoe.

 ■ vegetable	 ■ fruit	 ■ shake	 ■ entrée
 ■ red light foods	 ■ exercise	 ■ other green light foods	

The University of Kansas Diet Project
Diet Record

DIET RECORD					Week #
FRI	SAT		SUN		
food eaten		food eaten		food eaten	
					
					
					
					
					
					
					
					
					
					
					
					
steps: _____ 		steps: _____ 		steps: _____ 	
exercise type: _____ total exercise minutes: _____		exercise type: _____ total exercise minutes: _____		exercise type: _____ total exercise minutes: _____	

DIRECTIONS: The food items above the 1st blue dotted line represent the recommended foods to consume daily. Circle the pictures of the food items that you eat each day. If you eat more food items than there are icons to circle, please indicate the extra items next to one of the pictures (i.e. write x2 for 2 items consumed). You may also list what you ate next to the picture if you wish. Circle the shoe if you did planned exercise for at least 10 minutes consecutively. Also, list the type of exercise(s) you did and list the total exercise minutes you did that day. For example: exercise type: treadmill & elliptical, total exercise minutes: 30 min. Walking around the block for at least 10 minutes would count but walking at work in order to accomplish your job would not count. If you are using a pedometer, record your daily steps before bed each night next to the shoe.

 = vegetable	 = fruit	 = shake	 = entrée
 = red light foods	 = exercise	 = other green light foods	

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