Feedback and Strategies from Individuals with Intellectual Disability Completing a Personalized Online Weight Loss Intervention: A Qualitative Analysis

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Abstract

Coaching log notes for 15 participants from a 24-week blended online and telehealth randomized controlled trial were analyzed using thematic analysis and analyst triangulation to determine the factors that facilitated participant adherence to weight loss strategies, use of technology, and motivational interviewing. Several participants reported that restricting processed carbohydrates, limiting portion size, and maintaining healthy substitutions were effective nutritional strategies. Participants were less successful with adherence to their exercise goals, often due to time constraints and a lack of support. Results suggested consistent caregiver support improved participants’ adherence to weight loss strategies and use of technology. Future programs should address obesity among individuals with IDD by offering a range of interventions that are customized to their specific weight loss needs.

Introduction

Individuals with intellectual and developmental disabilities (IDD) experience higher obesity rates than their peers without IDD (De, Small, & Baur, 2008; Hsieh, Rimmer, & Heller, 2013; Maiano, 2011; Mikulovic et al., 2011). Excess body weight may result in health concerns across the lifespan. Obese adolescents with IDD are four times more likely than those without IDD to become obese adults, thereby increasing their risk of hypertension, type 2 diabetes and reduced life expectancy (George, Shacter, & Johnson, 2011; Gill & Fazil, 2013). Higher rates of obesity in adults with IDD are also accompanied by additional medical conditions, including cardiovascular disease, gastrointestinal and endocrine disorders, psychiatric diagnoses (e.g.,
affective mood disorders, anxiety disorders), and increased medication usage (Fisher, Hardie, Ranjan, & Peterson, 2017).

Current best practices for treating obesity include behavioral weight loss interventions, which are comprised of reduced caloric intake and increased physical activity. While there have been numerous assessments of behavioral weight loss strategies for the general population, a recent review of weight loss interventions for individuals with IDD concluded there is a paucity of comprehensive weight loss interventions designed for individuals with IDD (Harris, Melville, Murray, & Hankey, 2018). Individuals with IDD often encounter barriers for weight management that are related to transportation, access to facilities, financial concerns, and support (Heller, McCubbin, Drum, & Peterson, 2011; Pett et al., 2013; Saunders et al., 2011; Wu et al., 2010). In addition, conventional weight loss meal plans that are successful in the general population may be difficult for individuals with IDD to implement due to lack of understanding, co-morbid medical conditions, living arrangements, or other reasons (Ptomey et al., 2018). The current weight management practices for individuals with IDD do not provide sufficient guidance for individuals with IDD or their caregivers. Caregivers may lack formal training or support in assisting with weight management strategies for individuals with IDD. However, additional caregiver support has been positively associated with weight loss outcomes (Ptomey et al., 2017). Therefore, solutions to increase the communication of and adherence to weight management strategies in adults with IDD is a critically needed area of research.

Of the few clinically successful weight loss studies reported in the IDD literature, to our knowledge, only 2 studies have utilized technology (Lee et al., 2017; Ptomey et al., 2014). While technology can present challenges for people with IDD, it also provides opportunities, if developed appropriately, to increase the accessibility of conventional weight management
Interventions, promote adherence and retention, and eliminate major barriers. Surprisingly, there is little qualitative data on the perceptions of adults with IDD involved in a weight loss program. Therefore, it is important to obtain feedback regarding their perception of the use of technology to assist with weight management/weight loss interventions. To address this issue, feedback from a blended online health promotion intervention with support from a weight loss coach was analyzed. The system used in the intervention is referred to as the Personalized Online Weight and Exercise Response System for Individuals with Intellectual Disability, or POWERS for ID. The study is a 24-week randomized controlled trial (RCT), in which the intervention group has continual access to an online health platform and weekly (weeks 1–12) or biweekly (weeks 12–24) phone-based coaching sessions that include motivational interviewing (MI) strategies.

Participants receive information and resources about nutrition, physical activity, and behavioral strategies for weight management. In addition, intervention participants and caregivers may track weight management behaviors and goals through a customizable online interface, details of which have been previously published in Neumeier et al. (2017).

If technology-based (i.e., eHealth) weight management interventions are accessible and well received, they may be considered useful weight management intervention alternatives for individuals with IDD. However, feedback on weight loss programs from individuals with IDD and specific feedback on a program that utilizes technology have not been previously reported. Therefore, the aim of this paper is to report the participants’ perspective and feedback of factors, strategies, and behaviors that influenced participation in a weight loss intervention for individuals with IDD.

**Method**
This was an exploratory descriptive qualitative study that analyzed the POWERS\textsubscript{forID} coaching logs of documented phone, online, and face-to-face conversations. The following research questions (RQ) were developed to better understand the facilitators and barriers that adults with IDD experience during a technology-based weight loss intervention:

RQ 1: What diet and exercise strategies did participants select for weight loss?
RQ 2: What did participants indicate influenced their adherence to weight loss strategies?
RQ 3: How did participants interact with the online platform and related technology?
RQ 4: What did participants indicate facilitated coaching sessions throughout the intervention?

Setting and Participants

Individuals with mild to moderate intellectual disability who received healthcare services from a specialized clinic in the Colorado Springs, CO area were eligible for the study. Eligibility criteria included: a) adult with IDD 18 to 50 years of age; b) Body Mass Index $\geq 30$ kg/m\textsuperscript{2}; c) clearance from a medical provider to participate in a weight loss intervention; d) a caregiver willing to participate in a supportive role unless the participant served as own legal guardian; and e) access to a computer with internet throughout the week. Exclusion criteria included: a) already participating in a weight loss program and b) diagnosed with a medical condition that may interfere with weight loss and/or safe participation. Ethical permission was obtained through the Institutional Review Board at a university affiliated with the study, and all participants and caregivers provided informed consent to participate. Participants also received a physician’s release to ensure no underlying medical conditions would contraindicate participation.

Participants were randomly assigned to either a control group or the POWERS\textsubscript{forID} intervention. Baseline data for all participants included a blood draw for fasting lipids (repeated
at 24 weeks) and biomarker data to include body weight, body fat composition, waist circumference, and vitals (repeated at weeks 6, 12, and 24). Participants also completed a multi-faceted health appraisal profile (HAP). The HAP contained numerous questionnaires used to gather information about the participants’ demographics, health status and diagnoses, current physical activity and dietary patterns, psychosocial aspects, and functional abilities, as well as readiness to change (Heller, Hsieh, & Rimmer, 2004; Marks, Sisirak, & Heller, 2010). Research staff assisted participants who were unable to complete the HAP on their own. For all participants, the HAP created a baseline for further comparison and was repeated at weeks 6, 12, and 24.

The POWERS_{forID} intervention was conducted in a telehealth setting through weekly (weeks 1–12) and biweekly (weeks 13–24) coaching calls by phone and use of the POWERS_{forID} platform. The platform included a dashboard with links to educational resources, nutrition tips, a tracking journal to monitor physical activity and target food consumption, and a discussion board for communication between the participant and health coach. Each participant assigned to the intervention received a weight scale and pedometer to monitor their weight and physical activity levels. Their HAP information was used in POWERS_{forID} to generate tips for healthy eating and physical activity.

Setting exercise and diet goals was participant-driven. Based on information from the HAP and discussion with the participant and caregiver, the coach prompted participants on the following: 1) Select 1-3 high-carbohydrate target foods that they agreed to reduce or eliminate, and 2) Establish an exercise goal that the participant could reasonably and consistently fit into their schedule. These participants were oriented to the POWERS_{forID} website and coached on logging their intake of target foods and physical activity in the online journal. The coach used MI
techniques adapted for individuals with IDD (Frielink & Embregts, 2013) during coaching calls to support the individuals in developing strategies to meet their goals, goal management, and answer questions or concerns the participant might have. The coach securely stored coaching logs for each session within POWERS\textsubscript{forID}. Caregivers also had access to the POWERS\textsubscript{forID} platform to support their care recipient and often participated in coaching calls.

Participants assigned to the control group did not receive the telehealth intervention (coaching sessions and POWERS\textsubscript{forID} website access). At the conclusion of the 24-week study period, control group participants received a packet of educational materials attained from the National Center on Health, Physical Activity and Disability (NCHPAD), and information on how to contact a NCHPAD Information Specialist for advice on physical activity and nutrition. For more details information about the intervention protocol, see Neumeier et al. (2017)

**Data Collection**

Throughout the study, the weight loss coach maintained detailed logs about all communication, interactions, and events related to intervention group participants according to guidelines of the study protocol (Neumeier et al., 2017). The coaching logs contained comprehensive summaries for telecoaching sessions, emails, text messages, face-to-face interactions, and appointment scheduling. Data collection also included any stored online conversations between the participant and coach in the POWERS\textsubscript{forID} discussion board.

**Data Analysis**

At the time qualitative analysis was performed, 30 participants had been recruited and enrolled in the study. For this qualitative study, coaching logs and any available discussion board conversations for the intervention group only ($n = 15$) were analyzed. Participants who were still enrolled in the study were excluded. Two independent coders familiarized themselves with the
data before starting thematic analysis (Doody, Slevin, & Taggart, 2013). To reduce bias and enhance trustworthiness of the data, one of those coders was a research assistant who was not directly involved in this study. An iterative process of coding, recoding, and collapsing codes into themes was used to interpret relationships (Jonsen & Jehn, 2009; Petty, Thomson, & Stew, 2012). Preliminary analysis occurred during month 8 and month 14 of the study. It became evident that data saturation was achieved because no new themes emerged between month 8 and month 14. The coders independently reviewed and assigned codes to meaningful segments of text. The coders then debriefed by reviewing the list of codes they had each developed, and agreed on a final codebook. The final set of codes was used to analyze the entire dataset. Together, the coders collapsed codes into categories or subthemes, and then identified three overarching themes that the data represented. Although categories represented a unique aspect of the data, overlapping of categories occurred across the text. Overlapping categories helped to explain contextual meanings that were indicative of thematic relationships. Atlas.ti software was used for generation of co-occurrence tables that quantify the overlap of categories. However, note that St. Pierre and Jackson (2014) and Talanquer (2014) cautioned against establishing categories and themes solely based on frequencies because it could detract from contextual meanings. The researchers in this study considered frequencies and contextual meaning to develop relevant themes and subthemes. A content analysis matrix is available in Appendix A that includes the following information: a) samples from coaching logs that represent the themes/subthemes, b) the percentage of the coded dataset that is attributed to a particular theme/subtheme, and c) the percentage of participants for which a particular theme/subtheme emerged.

Results
Qualitative data for all 15 participants (P) in the intervention were analyzed for this study. Eleven participants completed the 24-week intervention and 4 participants withdrew from the intervention. Participant demographics at the time of enrollment are presented in Table 1. Also see Appendix B for coaching log samples that contain a summary of discussions between the participant and coach regarding diet and exercise strategies, technology, weight updates, and MI techniques. Appendix C contains a sample from the online discussion board.

[Insert Table 1]

**Diet and Exercise Strategies that Participants Used for Weight Loss**

During the intervention, participants established a diet and exercise goal that they could modify as needed. Participants reported greater success with adhering to diet strategies than to exercise strategies.

**Diet.** Among the participants who lost weight, the most common diet strategies used for weight loss were portion control, restricting processed carbohydrates, using substitutions of a lower calorie food in place of a higher calorie food, packing or preparing healthy meals, and meal timing. Participants indicated that using general concepts for portion control, such as eliminating second helpings, was more helpful than using portion control diagrams for meal planning. Additionally, participants were more successful when they identified target snack foods with a higher caloric density such as chips, soda, and desserts rather than items such as bread, pasta, and rice. Participants also found it helpful to maintain availability of low-calorie substitutions (e.g., fruit, vegetables, salads) instead of eliminating snacks to help curb hunger and cravings. Most participants who packed their lunches from home in place of eating out for lunch reported consuming smaller portions and less junk food than they would otherwise. However, a few participants reported struggling with snack choices when packing their own lunches. Two
Weight Loss Intervention

participants (P12 and P25) indicated they often ate late at night, and they found that establishing earlier dinners and avoiding late night snacks supported their weight loss goals.

**Exercise.** Participants reported using a broad range of exercise strategies (e.g., walking, cycling, Zumba, local fitness facilities). However, a review of the coaching logs indicated that implementing consistent exercise routines was the most helpful exercise strategy regardless of the exercise methods used (P8, P24, and P26). Participants who exercised fewer than three days per week reported a lack of weight loss but were resistant to increasing the frequency of their exercise routine. The findings of this study also indicated that starting a new exercise routine strained participants’ daily schedules more than modifying their eating habits. Two participants (P16 and P25) attributed their weight loss to diet strategies and reported limited exercise. Overall, participants and their caregivers showed more effort with diet strategies than with exercise strategies.

**Factors that Influence Adherence to Weight Loss Strategies**

Themes emerged regarding what factors participants identified as facilitating or hindering adherence to diet and exercise weight loss strategies during the intervention. Each factor related to the individual, the support they received, or the environment.

**Individual.** Several participants indicated that medical concerns (e.g., sleep apnea, epilepsy/seizure disorder), mental health diagnoses (e.g., depression, bipolar disorder, mood disorder, anxiety), and/or behavioral issues (e.g., substance abuse, anger management, formal restrictions) interfered with adherence to their diet and exercise strategies. Mental health and medical concerns typically presented as the participant lacking the energy or desire required to engage in meal planning or physical activity (P13 and P25), whereas behavioral issues presented as a preoccupation that distracted from the participants’ weight loss goals (P12 and P18).
Although psychotropic medications did not interfere with strategy adherence, P10 associated psychotropic medications with the lack of weight loss despite consistent adherence to diet and exercise strategies. Weight outcomes seemed to affect participants’ perceptions about their goals and strategies. For example, some participants who showed commitment to the strategies but did not see immediate weight loss expressed discouragement and reduced adherence to their weight loss strategies as noted in the following log note: “[P2] and [his caregiver] expressed disappointment with their efforts to lose weight. [P2] expressed a lack of motivation to exercise and eat differently because he has not lost any more weight.”

How a participant approached their weight loss goals and strategies also seemed to affect their adherence. For instance, despite the coach’s guidance to develop broad exercise goals (e.g., exercise 3 days per week for 30 min), some participants broke down the goal into more specific subgoals (e.g., 5-10 minute increments of 5 different exercises within 30 minutes), which later became too difficult to follow. A review of the coaching logs and participant accounts indicated that participants adhered to strategies more consistently when the goals and strategies were broad. A breakdown of participants’ withdrawal rate, diagnoses, and weight loss strategies by group are presented in Table 2.

[Insert Table 2]

**Interpersonal Support.** Most of the participants received formal support from either a residential caregiver or a day program provider. The data indicated that participants who lacked formal or consistent support felt they could have benefited from assistance with strategy adherence beyond that given by the weight loss coach. In fact, coaching logs reflected that inconsistent support and frequent staff turnover hindered weight loss strategy adherence. Areas in which residential caregivers in this study supported participants were primarily time
management, transportation, and engagement during exercise and meal planning or prepping activities. Coaching logs indicated that caregivers’ behaviors related to food purchases and meal planning affected participants’ adherence to diet strategies as reflected in the following note: “[P2] reiterated several times that the family does not eat healthy, so it is difficult for him to eat healthy meals.” Day program providers primarily supported participants’ adherence to exercise strategies by scheduling activities (e.g., hiking, fitness facilities) and providing transportation. Although day program providers had less involvement with diet strategies, their behaviors related to eating out influenced participants’ adherence to diet strategies. Overall, the findings of this study suggest that the level of caregivers’ health education and openness to change influenced the strategies they used to support the participant. Table 3 shows the frequency that a strategy was provided specifically by a caregiver or through a day program.

[Insert Table 3]

**Environment.** Participants reported that the environments in their homes, day programs, jobs, or schools influenced their adherence to diet and exercise strategies. For example, environments that lacked structure, were noisy, or were unstable hindered strategy adherence. Multiple participants (P8, P10, P13, P24, and P26) reported that having a job helped them increase their physical activity level. Conversely, all three participants who enrolled in college shared that participating in a weight loss intervention during the school semester was stressful for them, resulting in two participants withdrawing from the study to focus on school. P12 posted the following message on the discussion board, “…I am going to quit the weight loss program because I need to focus on college right now…” Also, a review of the coaching logs indicated that a break in routine caused by the weather, eating out, vacation, or moving to a new home created changes in the environment that disrupted strategy adherence for some participants.
Transportation and financial status also seemed to influence how participants interacted with their environments. Participants reported that a lack of money or transportation often limited access to fitness centers they were interested in joining.

Participants’ Interaction with the POWERS\textsubscript{forID} Platform and Related Technology

**eHealth Website.** The POWERS\textsubscript{forID} platform was originally designed for participants to be the end users. However, the findings of this study demonstrated the utility of the online platform for weight loss coaches as well.

*Coach.* The coach benefited from resources and tips generated through the POWERS\textsubscript{forID} website more than the participants did. Accessing resources through the online platform helped to ensure that the weight loss coach offered consistent guidance across cases. Further, the auto-generated tips from the online platform were based on participants’ individual responses to the health assessment profile completed at baseline, week 12, and week 24, thereby allowing the weight loss coach to offer individualized guidance to each participant. These tips were tailored to participants during telecoaching sessions when participants or caregivers asked specific questions and requested more information.

*Participants.* Six participants (40\%) reported not using the POWERS\textsubscript{forID} website. Participants who accessed the website generally used one of two sections, the discussion board or the tracking journal. A few participants found that navigating the website was confusing, but these participants also lacked caregiver assistance with the website. In those instances, participants either stopped using the website or entered inaccurate information. The findings of this study also indicated that participants became confused about which food items to report. If the specific brand had not been listed in the journal, then it often led to a delay, modification, or omission of information tracking by the participant or caregiver. For example, “[P4] was
confused about the concept of [reducing] chips [consumption]. The [coach] previously uploaded 3 different brands of chips that [P4 eats]. Now, [P4] thinks that she is meeting her goal by cutting down on Cheetos and replacing with another brand of chips [not listed].” In this case, using a generic image of chips could have been more effective. An example of the online journal tracking page is presented in Figure 1.

[Insert Figure 1]

Similarly, participants had difficulty tracking portions because they could not track less than one portion (e.g., half portions). Tracking smaller portions was also challenging for engaged caregivers, but the findings indicated that caregivers more readily problem-solved than participants did. Additionally, many participants reported barriers to computer use such as slow internet and insufficient support from family or staff as a prerequisite to accessing the POWERS<sub>forID</sub> website. For one participant, there was a single computer in high demand in a household of at least 7 people.

**Pedometer.** Most of the participants liked the concept of using a pedometer, and those who used the pedometer consistently reported that it was motivating. Some challenges that participants reported were incorporating the pedometer into their daily routines (P16, P18, P26 and P28) and consistently having a way to clip the pedometer to the waist (P10 and P15) so that it accurately recorded steps. The latter challenge was due to the design of the pedometer and the clothing worn by participants. Participants experienced battery failure and requested a replacement up to three times within a six month period, which interrupted step tracking. The coaching logs indicated that several participants and caregivers did not consistently reset the pedometer as instructed (i.e. once per week during the coaching call), which led to inaccurate weekly and daily step averages.
Factors that Facilitated Coaching Sessions

A review of the coaching logs indicated that the participant’s environment, using MI techniques, and caregiver engagement helped facilitate tele-coaching sessions during the intervention. A quiet and consistent environment in which participants could have a telecoaching session prevented disruptions during the call, thereby promoting greater progress. For example, the following note was documented about one participant’s experience, which illustrated the need for a quiet environment: “[P4] requested again to … see the [coach] face-to-face for sessions. When asked to explain why that would be preferable, [P4] stated the home is too loud and has too many distractions because there are so many people…” Similarly, consistent scheduling and completion of calls helped to maintain participant engagement and support the purpose of the telecoaching sessions. The study protocol included the use of MI to guide the flow of each coaching session. According to the coaching logs, MI helped to facilitate coaching sessions and engage the participant and caregiver, in particular, by the use of exploration and frequent or periodic summaries. Participation from an engaged caregiver typically helped with exploration of the participants’ circumstances and potential weight loss strategies. Caregiver engagement also enhanced sessions by sharing additional perspectives, helping maintain focus of some participants, and facilitating problem solving. Exploration during telecoaching sessions helped to overcome issues related to reporting bias in a supportive and non-threatening manner. On the other hand, the periodic summaries were more helpful with participants who were less engaged or did not have a caregiver involved in the study. In contrast to MI guidelines, the weight loss coach found that using close-ended questions often helped participants engage in conversation when open-ended questions did not stimulate a response (Frielink & Embregts, 2013).
Discussion, Implications, and Limitations

There are few weight loss interventions reported in the literature, and to our knowledge, only two studies have used an internet-based eHealth platform to deliver the intervention (Lee et al., 2017; Ptomey et al., 2014). Reports have indicated information technology is readily used by individuals with IDD, and expanded use of technology provides an opportunity to extend an intervention's reach among the IDD population (Tanis et al., 2012). However, little is known about participant receptiveness and use of weight loss interventions. Our analyses indicated participants utilized a blend of successful weight management strategies as well as revealed factors that should be considered in future interventions. Participants in this study preferred diet strategies to exercise strategies, which aligns with previous research that indicated more emphasis on diet than exercise (Stancliffe et al., 2011). Future studies should recognize the preference for diet, but also develop strategies to eliminate barriers to physical activity (e.g., greater individual context and supportive environments).

Future interventions should also account for comorbidities that may impact participation and adherence to weight loss interventions, and intervention staff should be trained in certain medical conditions and prescription medications that may impact weight loss. In the current study, participants reported adherence issues related to comorbid diagnoses. For example, people with comorbidities may feel too tired or fatigued to exercise, thereby increasing the risk of non-adherence to weight loss strategies and increased need for support. Table 3 illustrated that participants who maintained or gained weight engaged in more negative talk and perceived their medical or mental health diagnoses as a barrier to weight loss. Hsieh and colleagues (2013) reported on the comorbidities related to obesity in individuals with IDD, which align with the findings of this study in that individuals with IDD are at risk of developing obesity and should...
receive targeted weight loss interventions. Similarly, future research should address co-occurring IDD and mental health needs to better understand the supports needed by people with IDD to overcome related weight loss barriers. Our results support previous reports that behavioral issues also present barriers to implementing weight loss strategies (Gill & Fazil, 2013). Weight loss interventions for people with IDD should be designed to manage and redirect behavioral issues.

Inconsistent caregiver support or a caregiver’s lack of supportive health behaviors was identified as a barrier to weight loss strategy adherence. Diet, exercise, and caregiver attitudes and behaviors can affect weight loss success (George et al., 2011). Researchers agree that caregivers are most influential regarding healthy lifestyles through grocery shopping, meal planning, meal preparation, and exercise (George et al., 2011; Gill & Fazil, 2013; Ptomey et al., 2017). However, Ptomey et al. (2016) and Gill and Fazil (2013) found that caregivers were more willing to support weight loss strategies related to the individual’s diet (e.g., portion control, increased fruits and vegetables, and reduce eating out) than to exercise. Our analysis of feedback from participants with IDD supports these previous findings related to caregiver support. Caregiver preference for diet strategies may have influenced the observed participants’ preference for diet strategies. Caregivers may require additional training or assistance when managing a healthy weight and health behaviors for the individual with IDD. Alternately, additional support personnel, such as weight loss coaches, may assist the individual and caregiver (if applicable) with health-related behaviors. In addition, the level of caregiver support, self-efficacy of participants, and time constraints may influence weight loss, regardless of the type of caregiver (Ptomey et al., 2017). Results of this study support the level of caregiver involvement as a factor that influences participants’ adherence to weight loss strategies.
This study offers future implications for research and practice by accounting for the experiences of individuals with IDD in a weight loss intervention across different environments. Individuals with IDD who enjoy greater independence (Stancliffe et al., 2011) and spending money have more access to unhealthy food in the community than individuals who rely on caregivers (Gill & Fazil, 2013). Even though caregivers are frequently asked to facilitate more choices for people with IDD, they receive little guidance on promoting healthy lifestyle choices (Gill & Fazil, 2013). Factors such as income, neighborhood, safety, supervision level, and education regarding nutrition and exercise affect the engagement of individuals with IDD in a healthy lifestyle (Emerson, Hatton, Baines, & Robertson, 2016; Robertson, Emerson, Baines, & Hatton, 2014).

Based on the findings of this study, specialized training for promoting healthy lifestyles among people with IDD is warranted for all types of caregivers (e.g., residential staff, day program staff, and natural supports). In fact, Spanos, Melville, and Hankey (2013) suggested that successful weight loss interventions require teams who engage in consistent communication and implementation across settings to establish supportive environments. A review of the literature showed that most weight loss interventions take place in a single setting. Therefore, the findings of this study support the need to implement weight loss interventions seamlessly across residential and day program settings with communication among the various support roles.

The findings of this study demonstrated that using an online platform is a value-add resource to the weight loss coach, but there is also a need to continue improving the technology platform used by people with IDD for weight loss interventions. Future studies should continue to explore newer and more user-friendly technology through apps and fitness monitors that are compatible with various devices such as smart phones and tablets. To avoid the challenges
encountered when using a website, participants with IDD might use calorie tracking apps that use scanners to record information directly from nutrition labels. Adults with IDD have demonstrated adherence to pedometers, for example, but have demonstrated less success with accurately recording the step data (Ptomey, Willis…et al., 2018). To reduce those challenges, participants might use activity monitors that remind them to move around after a sedentary period or automatically store the data in a user-friendly app. There is always risk that such technology may already be outdated when reporting on technology-based interventions. Researchers and practitioners must also consider the training and support needed to help participants overcome their individual learning curves when using new technology and varying levels of interests in using technology. Therefore, it may be necessary to offer a range of delivery systems comprised of traditional and contemporary platforms for weight loss coaching interventions (e.g., face-to-face, phone-based, text-message based, online platform, apps, trackers) to meet individuals’ unique needs and skills related to weight loss strategy adherence. Doing so would be a more culturally-competent approach while increasing the accessibility of weight loss interventions.

A limitation of qualitative studies is researcher bias. In this study a single researcher recruited participants, acted as weight loss coach, and collected the data. To safeguard against bias, the researcher followed the study protocol and data integrity was periodically reviewed by the overseeing project coordinator. Additionally, a second coder who had not been involved in the study independently reviewed and coded the data later to compare notes with the original researcher (analyst triangulation). The researcher made efforts to remain neutral and not influence answers when asking participants study-related questions. Recall bias is a potential limitation in that log notes were finalized after the coaching interactions. For this reason, log
notes were documented as soon as possible following coaching calls. The small sample size from a single recruitment site was a limitation that can be overcome through multisite recruitment efforts.

Conclusion

This is one of the first studies to analyze participants’ perspectives and experiences regarding weight loss. Adults with IDD have unique needs to consider in addition to having many of the same challenges that adults without IDD face during weight loss interventions. Therefore, future weight loss programs could offer a broader range of interventions, including technology-based strategies, to meet individual needs related to weight loss success. Weight loss programs could also account for individuals’ level of support needed through caregiver education as well as continuity across settings for greater success with weight loss. Continuing research in this area will help to inform best practices that IDD professionals can apply when promoting healthy lifestyles as well as increase autonomy of many adults with IDD.

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References


Appendix A: Content Matrix Analysis

Table A.1. Adherence Factors Related to Participants’ Weight Loss Strategies and Selected Examples from Coaching Logs (n=15)

<table>
<thead>
<tr>
<th>Theme</th>
<th>% Coded Dataset</th>
<th>% Participants Citing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adherence factors related to the individual</td>
<td>25.6%</td>
<td>100%</td>
</tr>
<tr>
<td>Subtheme: Behavioral and Mental Health</td>
<td>8.7%</td>
<td>53.3%</td>
</tr>
</tbody>
</table>

[P13] When discussing what [strategies] he wants to continue working on, P described that there is “good weight” and “bad weight,” which he knows about “from spending all those years in the Marines.” However, P was never in the Marine Corps. He does have a diagnosis of bipolar and a [history of substance abuse].

[P25] P sounded motivated today about getting on track with her goals. She stated that she recently experienced a few episodes of depression, during which she eats and sleeps a lot. RC noted that P has been sleeping when contacted for coaching sessions. Episodes last from 2 days to 5 days.

Subtheme: Perception

[P16] CG stated that [P] wears pants size 38-40. However, CG has P’s pants size 36 stored in the basement, and plans to pull them out soon … P is very excited by the idea of wearing his new size. Watching the scale drop has been very motivating for P to continue making healthy, low-carb food choices.

[P24] He stated that he feels his muscles getting stronger, increased endurance, and uphill is much easier now … He wants to continue losing weight but stated that he feels he eats healthy and exercises enough.

Subtheme: Medical

[P13] [P was seen] at the emergency room on three separate dates within a one-month period for 1) GERD/esophagitis, 2) hematemesis with bright red blood—diagnosed as Mallory Weiss tear, and 3) generalized abdominal pain and constipation. He will follow up with the gastroenterologist…RC’s observation has been that P does not eat a healthy diet but is resistant to address any foods that he is eating. He is only willing to discuss the need to reduce soda. RC will attempt to explore his food habits more, and do a 24-hour recall if he is willing to participate in that during our next session….Lately, he began to drink soda again. P stated that he “drinks soda even though it tears [his] stomach apart because it makes [him] feel better.”

[P29] P and CG withdrew from the study today. CG expressed that she is overwhelmed with managing P’s complex medical needs. He started therapy for his back today. The therapist recommended back stretches that are very challenging for P. During stretches, he turns purple from lack of oxygen but refuses to wear his oxygen mask while at home. On some days, P cries because his knee hurts. P has been refusing to walk, exercise on the stationary bike, and do chores. CG wants P to lose weight but was concerned about his health and safety; therefore, she did not want to push him too hard.

Subtheme: Cravings and Hunger

[P08] Week 8: P is having sweet cravings so she eats fresh fruit. P stated that the fresh fruit really doesn’t curb her craving, but she has managed to stay away from sweets (i.e. candy, cake, donuts) [this past week].

[P08] Week 17: CG also shared that P is doing really well with avoiding carbs
and eating more fruit. In fact, P stated that she sometimes “craves fruit” like melon, oranges, and bananas. P stated that often a “sandwich doesn’t please me” and she opts for fruit instead.

### Adherence factors related to interpersonal support

<table>
<thead>
<tr>
<th>Subtheme: Caregiver Support</th>
<th>42.6%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>[P16] His mom also eliminated some foods from her diet. P and CG [mom] have been a strong support for one another. P eats a lot of salads when he visits his grandparents. Also, CG buys diet Hansen’s root beer for when P needs a low calorie treat. P shared that his aunt recently lost 10 lbs and is currently living with his grandparents to care for them; therefore, his aunt is also supportive of P’s goals.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subtheme: Day Program Support</th>
<th>9.5%</th>
<th>66.7%</th>
</tr>
</thead>
<tbody>
<tr>
<td>[P26] …P participated in tennis practices and walking. He also started vacuuming his room. CG might ask him to vacuum other areas of the house to help increase his physical activity level.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subtheme: Health Education</th>
<th>5.8%</th>
<th>80.0%</th>
</tr>
</thead>
<tbody>
<tr>
<td>[P02] While the family has put a lot of effort into addressing the types of snacks that P consumes, meals often contain high carb items. P reiterated several times that the family does not eat healthy, so it is difficult for him to eat healthy meals. Mom [CG] stated that P is in fact the healthiest adult in the family at this time.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subtheme: Time Management</th>
<th>2.5%</th>
<th>46.7%</th>
</tr>
</thead>
<tbody>
<tr>
<td>[P13] He currently does not access the university gym. He currently attends classes at school on Mondays, Tuesdays, and Thursdays; therefore, he could access the gym on those days. However, adding something new to his schedule during a transition period is not feasible at this time…His new home is further away from school, so P estimated that the bus route, including transfers, would take 1hr and 45 minutes for a one way trip to get to the fitness center at school.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Subtheme: Break in Routine</th>
<th>31.8%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>[P19] Mom/CG suggested that P could spend some time on the POWERS website this week since she is on Spring Break. Mom explained that adding a new routine into their schedule is just hard with the website, but do not mind having the phone calls.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
[P10] P has not been walking in the neighborhood due to the weather. Last week the temperature significantly dropped. This week, high winds were hazardous.

[P08] CG stated, “P had made arrangements to go to the YMCA, but then a friend called and asked her to go to Olive Garden with her instead. P was very quick to change her plans.”

### Subtheme: Residential

7.9% 73.3%

[P18] P stated that he has not exercised because there is a lot of gang activity in the neighborhood where he is staying; therefore, he cannot go outside for walks.

[P13] P immediately shared that he is at a different respite home this week. P does not know when he will return to the host home that he recently moved in to. He seemed confused about whether or not he would even return to that host home. P’s home life continues to be very unstable as he continues to move to different homes. He also shared that he failed his first semester with college, elaborating that his grades dropped when he started moving from host home to host home.

### Subtheme: Transportation

5.1% 53.3%

[P02] [CG] relies on the services that [P] has and [the agency] pays for those services … P is having some challenges with one of his day service providers regarding accessing the community. CG feels that this service provider has not been supportive of P’s desire to be more physically active by taking him to the movies instead of fitness related activities.

[P08] P independently accesses the YMCA through Metro Mobility rather than relying on others to access the YMCA and work toward her goals.

### Subtheme: Job

4.0% 53.3%

[P10] P reported that she currently engages in zero exercise. The extent of physical activity is at her job where she works approximately 2 hours on 2 days per week serving food at a school cafeteria.

[P13] Currently, he works 4-hour shifts a few days per week, during which he remains active the entire time. During the shift, he washes dishes, cleans bathrooms, disassembles/cleans/reassembles the industrial size dishwasher.

### Subtheme: Financial

3.5% 46.7%

[P02] CG stated “I wish I could spend more time with my son. But you know, there are so many things on my mind. I have to survive and pay the bills. I rely on the services that he has and TRE pays for those services.”

[P13] [CG] was looking into funding that would help P either get a membership… P and CG decided not to join a gym because P has access to the school fitness center and the YMCA. He also has free weights at home.

### Subtheme: School

3.1% 20%

[P12] P stated, “HI RC, I am going to Quit the Weight Loss Program because I need to Focus on College right now and the Weight Loss Program is Stressing me Out and I can't do Appointments at [clinic] right now because I need to Focus on School.”

[P19] CG explained that P had breakthrough seizures and was seen at the emergency room. A new medication was prescribed. Stress seems to be a trigger for P, which has heightened since P started participating in POWERS and school simultaneously. Presently, P needs to focus on the final 2 weeks of the semester. CG requested for P to be temporarily withdrawn from the study and resume POWERS in the summer.
Appendix B: Coaching Log Samples

Participant A

3/10/17 – tele-coaching session lasted 24 minutes today. CG explained that P reads the weight off by 1 digit because he includes the decimal point. She clarified that last week, P weighed 217.5 lbs., not 175 lbs. This week, P weighed 214.2 lbs. P continues to lose weight steadily. He did not wear his pedometer this week. CG tracked information in the journal; therefore, RC issued incentives for this past week. CG also stated that she will complete the food frequency today.

EXERCISE: P incorporates walking into his routine. He walks with day program and on the weekends such as at the mall. Also, one of the day programs has a fitness room where he used the treadmill and elliptical machines. He did not use the treadmill at home this week. He does not seem that interested in using it, although he did get on the treadmill while on the phone with RC today.

NUTRITION: CG stated that she is very proud of P and the great food choices that he is making. P stated that he is not eating bread, sweets, chips, etc. He eats a lot of fruit and salads with meat such as grilled chicken. He also makes good choices in the community. For example, he spends a lot of time with his grandfather and his grandfather’s friends who eat a lot of pastries. When they eat pastries/Danishes, P opts for fruit. Day program has cooking activities on Fridays. P opts to take his own lunch when he knows the activity will be an unhealthy food choice. He also takes his lunch if he does not know what day program will cook that day just in case it’s not a healthy choice.

SUCCESSES/CHALLENGES: P shared that his clothes fit better. CG stated that he wears pant size 38-40. However, CG has Ps pant size 36 stored in the basement, and plans to pull them out soon for P. P is very excited by the idea of wearing his new size. Watching the scale drop has been very motivating for P to continue making healthy, low-carb food choices.

MOTIVATIONAL INTERVIEWING: RC used open-ended questions and reflective listening throughout the session. Made several affirmations regarding Ps ability to sustain making healthy food choices in various settings. RC respected Ps autonomy to make choices regarding exercise routines. Ended the session with a summary of the strategies and progress that P has made.

Next session scheduled for 3/17/17 at 845am.

RC – Research Coordinator
P – Participant
CG – Caregiver

Appendix C: Online Discussion Board Sample
[Participant] thinks that eating potatoes is not like eating potato chips. I was under the impression that she wasn't to eat a lot of potatoes. I haven't been counting the potatoes because of this, but next time you call [Participant] let her know if it is the same as eating potato chips. That is if it is the same.

[Caregiver] (11/27/2016 12:07pm)

Hi Ladies! Yes, potatoes of any kind are starchy/carbohydrates. Eating natural potatoes are better than eating potato chips, but still a carb. And remember portion control...if you eat too many potatoes, it could be more calories than eating a bag of potato chips. We can definitely explore this more when we talk this week. Feel free to send more questions any time.

[Coach] (11/28/2016 2:42am)

Hi, here are some videos on YouTube that you might enjoy for home exercises. Let me know what you think of them. You can just copy and paste the URLs below into your internet browser.

http://tinyurl.com/POWERSwarmup
http://tinyurl.com/POWERSactivity2
http://tinyurl.com/POWERSactivity3
http://tinyurl.com/POWERSbands - [Coach]

[Caregiver] (11/29/2016 1:48pm)

No problem. Just highlight the following: http://tinyurl.com/POWERSactivity2. Then right click your mouse, select copy. Then go to the top where you usually find website, and right click, select paste. Then hit enter.

[Coach] (11/30/2016 5:14am)
Table 1

*Participant Characteristics at Enrollment (n = 15)*

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Parameter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>53%</td>
</tr>
<tr>
<td>Female</td>
<td>47%</td>
</tr>
<tr>
<td>Age (years)</td>
<td>32.53 ± 4.88</td>
</tr>
<tr>
<td>Starting BMI (kg/m²)</td>
<td>37.72 ± 6.68</td>
</tr>
<tr>
<td>Enrolled with a caregiver</td>
<td>n = 9</td>
</tr>
<tr>
<td>Attended day program</td>
<td>n = 10</td>
</tr>
<tr>
<td>Part-time job</td>
<td>n = 7</td>
</tr>
<tr>
<td>Enrolled in ≥1 college course</td>
<td>n = 3</td>
</tr>
</tbody>
</table>
Table 2

Weight Status, Diagnoses, and Weight Loss Strategies of Participants Enrolled in the POWERS for ID Intervention (n = 15)

<table>
<thead>
<tr>
<th>Weight Status &amp; Weight Change</th>
<th>Delta weight (kg)</th>
<th>Withdrawal Rate</th>
<th>Intellectual/Developmental Disability Diagnoses</th>
<th>Co-morbid Medical Diagnoses</th>
<th>Mental/Behavioral Health Diagnoses</th>
<th>Perceived Diagnoses as a Barrier to Weight Loss</th>
<th>Behavioral Weight Loss Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maintained/Gained Weight</td>
<td>.54 ± .41</td>
<td>50%</td>
<td>Unspecified Intellectual Disability, Laurance Moon Biedl syndrome, Pervasive Developmental Disorder, Down syndrome, Traumatic Brain Injury</td>
<td>Seizure Disorder, Obstructive Sleep Apnea, Hypoxemia, Vitamin D deficiency, Dyslipidemia, Thyroid disorder, Type 2 Diabetes, GERD</td>
<td>Bipolar Disorder, Mood Disorder, Anxiety, Depression, Obsessive Compulsive (OCD) Disorder</td>
<td>100%</td>
<td>Portion control, packing healthier meals, establishing broad exercise goals</td>
</tr>
<tr>
<td>Reduced Weight</td>
<td>-4.25 ± 3.01</td>
<td>11%</td>
<td>Unspecific Intellectual Disability, Autism, Asperger syndrome, Fragile X syndrome</td>
<td>Seizure Disorder, Obstructive Sleep Apnea, Hypoxemia, Vitamin D deficiency, Dyslipidemia, Thyroid disorder, Type 2 Diabetes, GERD, chronic constipation, Insomnia</td>
<td>Bipolar Disorder, Mood Disorder, Anxiety, Depression, OCD, Impulse Disorder, Schizoaffective Disorder, Marijuana use, Attention Hyperactive Deficit Disorder</td>
<td>22%</td>
<td>Used portion control, restricting processed foods, using lower-calorie substitutions, packing healthy meals, meal timing, broad exercise goals (e.g., cardio for 30 min on 3 days per week), and a consistent exercise schedule.</td>
</tr>
</tbody>
</table>

Note: Participants that maintained weight were defined as those who had a net weight change of less than 0.45 kg or 1.0 lbs. during the intervention. The group that maintained weight displayed a higher withdrawal rate than the group who lost weight. Both groups have numerous diagnoses listed in all categories, however, the group that maintained/gained weight engaged in more negative talk related to diagnoses and a lack of weight loss and used fewer weight loss strategies than the group who lost weight.
Table 3

Co-occurrence of Weight Loss Strategies and Type of Support (Frequency)

<table>
<thead>
<tr>
<th>Type of Support</th>
<th>Caregiver Support</th>
<th>Day Program Support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diet Strategies</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meal Planning</td>
<td>17</td>
<td>1</td>
</tr>
<tr>
<td>Portion Control</td>
<td>17</td>
<td>0</td>
</tr>
<tr>
<td>Restricting high-carb food</td>
<td>29</td>
<td>6</td>
</tr>
<tr>
<td>Using lower-calorie substitutions</td>
<td>23</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>86</strong></td>
<td>8</td>
</tr>
<tr>
<td><strong>Exercise Strategies</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access to Fitness Center/Activities</td>
<td>9</td>
<td>42</td>
</tr>
<tr>
<td>Broad exercise goals</td>
<td>10</td>
<td>14</td>
</tr>
<tr>
<td>Consistent exercise schedule</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>31</strong></td>
<td>66</td>
</tr>
</tbody>
</table>

*Note:* In Table 3, the frequency is listed for each weight loss strategy by caregiver and day program support. Co-occurrence data was generated through Atlas.ti. The data in Table 3 shows caregiver support involved diet and exercise strategies, but the type and frequency of diet strategies was greater than that of exercise strategies. In contrast, Table 3 shows that day program support focused more heavily on exercise strategies, with minimal involvement in diet strategies.
Figure 1

POWERS_forID Journal Screenshot: Tracking Exercise and Eating Behaviors

Note. Figure 1 illustrates the journal page for tracking physical activity and target food consumption from the POWERS_forID online platform and includes an example of how the weight loss coach could insert images of brand name or food items for the participant to log.