Piloting of a Health and Wellness Hub

for

Adults with Developmental Disabilities

**Report Summary** 

Prepared by

Chwen Binkley, RD, MSc

April 20, 2019

**Options for Independent Living and Development** 



## Funding

The *Piloting of a Health and Wellness Hub for Adults with Developmental Disabilities* project is funded in part by the Government of Canada's Homelessness Partnering Strategy's Innovative Solutions to Homelessness.

# Canada

The opinions and interpretations in this publication are those of the author and do not necessarily reflect those of the Government of Canada.

## Acknowledgements

Special thanks to Options for Independent Living and Development (OFILD) and Community Residential Care Homes (CRCH) for their support of the project. We also extend our special thanks to all research participants who participated in interviews and focus group. Kathleen Ward is the funder of Community Residential Care Homes and inspired the development of this Health and Wellness Hub. Michael Power is the President of Options for Independent Living and Development and was the project coordinator for this initiative.

## **Table of Contents**

Executive Summary	4
1. Background	8
1.1 Introduction	8
1.2 Purpose	10
1.3 Research Questions	10
2. Literature review	12
2.1 Health Matters Program	12
2.2 Health Education Learning Program (HELP)	13
2.3 The Healthy Lifestyle Change Program (HLCP)	,,
2.4 Steps to Your Health Program	14
2.5 The STOP Prevention Program	15
2.6 The Universal Health Intervention Sweden	15
2.7 The Wellness Club	16
3. Research Methods	19
3.1 Research Setting	19
3.2 Research Design	19
3.3 Data Collection Tools	23
3.4 Data Analysis,	,24
4. Key Findings	26
4.1 Study Participants	26
4.2 Results Participant Questionnaires	27
4.3 Results of Past Participant Interviews & Focus Group Meeting	31
5. Discussion	38
6. Limitations of the Study	40
7. Conclusion:	41
References	43

## Appendices

Appendix 1:Interview Guide for Participants with DD	46
Appendix 2: Focus Group Guide	48
Appendix 3: Nutrition Knowledge Questionnaire	51
Appendix 4: Cooking Skills Questionnaire	56
Appendix 5: Life Skills Questionnaire	58
Appendix 6: Physical Activity Log Sheet	59

## List of Figures

Figure 1. Nutrition Question Pre-and Posttest Outcome	27
Figure 2. Summary of Pre/Post Cooking Efficacy Questions	28
Figure 3. Summary of Pre/Post Life Skills Questionnaire	29
Figure 4. Summary of Physical Activity Frequency	.30

## **Executive Summary**

In response to efforts by the Employment and Social Development Canada (ESDC) to preventing and reducing homelessness in Ontario, Options for Independent Living and Development (OFILD) in Hamilton set out to pilot a health promotion initiative, namely, *the health and wellness Hub for Adults with Developmental Disability*, to help address the significant and continuing need for stable housing for adults with developmental disabilities who may also have other behavioural and mental health challenges. Stable housing, with appropriate supports, is a necessary condition to the personal development and well-being of individuals with developmental disabilities (DD). Although adults with DD may have housing (and many do not as per the provincial waitlist), if their needs are not met adequately, they are more likely to have an increased chance of becoming homeless. In order to provide stable housing and supports for individuals with complex needs, we need to explore innovative ways to address housing needs for this vulnerable population.

### Purpose

The aim of this study was to develop, pilot, and evaluate the effectiveness of an onsite health and wellness hub in increasing knowledge about healthy eating, life skills, and frequency of physical activity among adults with developmental disabilities living in supported-living arrangements. The study also explored the

perceptions of participants and team leaders/support workers involved in the pilot regarding their experiences with and perspectives about the health and wellness hub and possible areas for improvement.

## **Methods**

The study used a combination of quantitative and qualitative designs for data collection. Questionnaire was the primary method used for quantitative method to determine impact of interventions on program participants. For qualitative method, individual interviews and focus group were used to explore study participants' views about the health and wellness hub. Sixteen adults with DD took part in the pilot study and 14 of them participated in individual interviews. Six team leaders/support workers attended focus group discussions. Concurrent data collection and analysis, data saturation, and a constant comparative method guided the research.

## **Key Findings**

The quantitative data showed that the majority of program participants have increased their knowledge about healthy eating and confidence about their ability to perform basic life skills after the intervention. They have also engaged in physical activity more often during the pilot period. Results of the qualitative study demonstrated that all study participants had positive experience with the

wellness hub. In particular, they enjoyed the learning and social opportunities that came with the creation of the hub. The team leaders reported that they witnessed increased healthy behaviour and strengthening of bonding among program participants.

Several challenges related to the implementation and program delivery during the pilot were identified i.e., limited space for program activities, staffing constraints, program scheduling, and participants needing constant reminders and sometimes physical assistance to get to classes. The team leaders/support workers also highlighted some areas for improvement which included scheduling regular time to meet with program participants to review goals and progress; maintaining ongoing communication among team leaders, and providing opportunities for participants to practice skills learned. There suggestions for program sustainability were: to assess specific activities that can be continued within the current budget allowance (all activities do not need to be sustained, just the ones that are intended to achieve desired outcome); strengthen current partnerships; explore potential collaborations (both public and private), and involve key stakeholders including program participants, family members, caregivers, and staff members in program activities.

## Conclusion

An on-site health and wellness hub that offers support, coordinated services and a variety of health promotion activities do assist individuals with DD to adopt a healthy lifestyle, develop life skills, achieve personal goals, develop and strengthen positive relationship with friends, and participate in meaningful activities. All of these will lead to increased levels of housing stability.

The Health and Wellness Hub offers a unique idea for organizing in-home health promotion supports for adults with DD in supported living environments. Organizations wishing to adapt or incorporate some aspects of the current model into their existing program for adults with DD should first determine how large of the scale their program will be in order to identify key staff and resources needed to manage the program.

Implementation of a health promoting program requires commitment from organization, resources, capacity, and ongoing support from the staff to carry out the planned project. Nevertheless, the availability of this type of wellness program can help address housing instability and many health concerns facing adults with DD.

## 1. Background

## **1.1 Introduction**

Housing is a basic human right and is essential to health and wellbeing of an individual (Ontario Human Rights Commission). Current literature indicates that individuals with developmental disabilities (DD) are at greater risk of experiencing homelessness and housing instability as well as mental health issues compared to people without a disability (Backer and Howard, 2007, Johnson, 2016). In fact, it was reported that a disproportionate number of the homeless individuals are persons with developmental disabilities in Canada (Bach, M, 2011, Durbin, 2018). We also know from literature that people with DD are more prone to develop multiple chronic conditions and are often excluded from community-based health promotion programs (Scott, H & Havercamp,SM, 2016). A lack of focus on wellness and preventive health has placed people with DD at greater risk for poor health (Anderson, 2013). There is clearly a need to address some of these issues for this vulnerable population.

In response to efforts by the Employment and Social Development Canada (ESDC) to preventing and reducing homelessness in Ontario, Options for Independent Living and Development (OFILD) in Hamilton set out to pilot a prevention model to help address the significant and continuing need for stable housing for adults with DD who may also have other behavioural and mental health challenges. Stable housing, with appropriate supports, is a necessary

condition to the personal development and well-being of people with DD. In order to provide stable housing and supports for people with urgent and/or complex needs, housing and support services providers need to look for innovative ways to address housing shortages.

OFILD has over 40 years of experience in the field of homelessness prevention and reduction through the provision of stable housing and support services, primarily for individuals with DD who may also have other behavioral and multiple co-morbid psychiatric disorders. Many of its residents experienced or were at risk of homelessness in their past, some of them were either abandoned, on and off the street, or inappropriately housed in hospitals. Over the years, OFILD has demonstrated that it is possible to help support individuals with DD to improve housing stability, self-sufficiency, community inclusion, and overall quality of life by providing person-cantered care and support and by partnering with families, local neighbourhood community and various cultural, education, and social facilities.

OFILD embraces innovated health promoting models that will improve the wellbeing of its residents. The organization believes that this pilot project will help contribute to housing stabilities and retention among individuals with DD.

## 1.2 Purpose

The objective of the project is to develop, pilot, and evaluate the effectiveness of an onsite health and wellness hub in increasing nutrition knowledge, life skills, and levels of physical activity among adults with DD and mental health and/or addiction challenges living in supported-living arrangements. Additionally, the study explores the perceptions of participants and team leaders/support workers involved in the pilot regarding their experiences with and perspectives about the health and wellness hub as well as possible areas of improvement.

## **1.3 Research Questions**

This project focuses on the following key questions:

- Will an onsite health wellness hub help increase access to health promotion activities among program participants?
- How will the participation of health promotion activities offered at the wellness hub impact the program participants?
- Will the participation of health promotion activities offered at the wellness hub help participants gain knowledge, strengthen life skills, improve selfefficacy, increase levels of physical activity, or improve eating behaviours?
- Does the centralized wellness hub help improve the efficiency of service delivery?
- What are the perceptions of the participants and the support workers/team leaders about this health and wellness hub?

• What recommendations do the participants and support workers have to improve their experiences with and the services and delivery of the health and wellness hub?



## 2. Literature Review

A preliminary literature review was conducted to exam existing research on wellness and health promotion initiatives targeting adults with developmental disabilities. For the purpose of this review, only multi-component interventions (interventions incorporating at least two health promotion activities, such as nutrition/health education, physical activity, cooking, or health screening) were explored. Below is a summary of exemplary wellness initiatives that have been offered to this target audience.

## 2.1 HealthMatters<sup>™</sup> Program

This is a curriculum-based health promotion program designed specifically for adults with developmental disabilities. The Social Cognitive Theory and the Transtheoretical Model of Behavior Change are used to provide a framework for structuring activities for service providers and participants. The program is 12 week long, 3-day a week and includes exercise, nutrition and cooking classes, and health education components. The class is two hours long with one hour dedicated to group exercise. Results of a randomized efficacy trial with 53 adults with Down syndrome demonstrated positive outcomes such as increases in positive attitudes towards exercise, increased life satisfaction, decreased risk for depression. Training and support are available for organizations interested in the implementation of the program.

## 2.2 Health Education Learning Program (HELP)

The HELP program was an eight-week cardiovascular health program developed by a medical doctor. The curriculum covered topics in exercise, nutritional choices and stress reduction and can be used by both individuals with developmental disabilities and without disabilities. The program took place at a primary care center and was facilitated by two health educators. Participants attended a weekly 90-minute class followed by an optional brisk walk with the instructor. The instructor visited each participant twice during the program to help them establish an exercise program, develop a dietary plan and make healthy food choices via a grocery shopping tour. Evaluation results demonstrated positive outcomes such as weight loss and reduced BMI. Follow up study also showed sustained healthy behaviours (McDemott, 2004)..

## 2.3 The Healthy Lifestyle Change Program (HLCP)

The HLCP was a community-based, comprehensive group health promotion program targeting adults with DD who were overweight/obese and experienced other health risks. Its conceptual model was based on social cognitive theory of health behavior change which focused on self-efficacy, positive reinforcement, and peer mentoring. The program was 7-month, twice-weekly education and exercise program with peer mentors served as participant leaders and primary motivators. Each class included 50 minutes of interactive health education, a 10minute healthy snack break, and one hour of supervised physical activity. A evaluation of the program (Bazzano, AT, 2009) demonstrated many positive outcomes of attending the HLCP program including improved lifestyles, weight loss success, improved nutrition, increased exercise frequency, increased selfefficacy, improved access to care for a group of adults with DD and increased community capacity. This project demonstrated that a successful, communitybased healthy lifestyle intervention can be developed and sustained with the participation of the developmental disabilities community.

## 2.4 Steps to Your Health

The Step to Your Health (STYH) was an eight-week health promotion program developed specifically for adults with developmental disabilities. The program used participatory model and social-cognitive approaches and emphasized physical activity, healthy eating, and Body Mass Index (BMI) reduction. Each class was 90-minute long facilitated by a trained health educator and included discussions, practice activities, healthy snacks and a short walk. Results of a randomized efficacy trials (McDermott, 2012) showed that participants did not have a significant increase in there physical activity or mean BMI one year after classes ended. However, the study found participation in STYH classes had a non-significant association with odds of reduction of BMI. Further, adults with DD living in group homes were more likely than those who live with families or in supervised apartments to decrease their BMI.

## 2.5 The STOP Prevention Program

This was a multi-component lifestyles behaviour change program targeting adults with developmental disabilities with a high risk of developing type 2 diabetes and/or cardiovascular disease. A combination of theories including Theory of Planned Behaviour and Reasoned Action were used to inform the development of the program. The program was facilitated by two health educators and consisted of one initial session with caregiver, followed by seven joint weekly education sessions for the individuals with DD and their caregiver/spouse/partner in a community setting. The curriculum for the participant and caregiver sessions addressed topics related to health, physical activity, and nutrition. A feasibility study of the STOP program (Dunkley et al. (2017) suggested a general trend towards improvement in biomedical measures. Participants reported positive dietary changes and increase in physical activity, however the result was only based on a very small sample size.

## 2.6 The Universal Health Intervention - Sweden

The intervention was based on Social Cognitive Theory and aimed to improve diet and physical activities among people with DD. It included three components: (1) appointment of a health ambassador in each community residence attending network meetings, (2) a study circle with ten 90-minute sessions for caregivers to discuss and plan their health promotion work in the residence, and (3) a health course with 10 sessions on health, healthy foods and physical activities for the residents. The intervention was 12-16 months long. A cluster randomized controlled trial (Sundblom, 2015) was conducted to evaluate the effects of the intervention. A total of 129 participants aged 20-66 years old from 30 developmental disabilities community residences in Stockholm, Sweden completed the study. A positive intervention effect was found on physical activity and work routines (for meals, physical activity, and health from managers and/or caregivers). Positive work routines indicated that this approach might be an effective way of improving health behaviours in community residences, although the effect size was small. No significant effects were found on BMI, waist circumference, dietary quality, or satisfaction with life. The researchers concluded that greater effects could be achieved by improving implementation strategies.

## 2.7 The Wellness Club

This was a health and wellness intervention targeted adults with DD living in supported arrangements to prevent and manage secondary conditions (The University of Montana Rural Institute, 2010). The intervention was based on behaviour modification techniques and consisted of general health education, individual planning, various assessments, self-monitoring, and standard mechanisms for reinforcing healthy lifestyle behavior.

Residential service providers worked with individuals they support to help them set relevant personal goals, develop a program with objectives and support activities to achieve the objectives. They provided prompts and reinforcement for targeted health behaviors.

The Wellness Club model was widely used as the basis of treatment services in the national network of supported living programs and have consistently been shown to be effective. The program was evaluated by University of Montana and the University of Kansas, however, results of the study was not published.

## Conclusion

This short literature review provides some valuable information to inform practice and implementation of health promotion programs that align with evidence. Evidence from these multi-component interventions have been shown to improve physical health, improve nutrition, improve life styles, enhance quality of life, reduce BMI, improve health behaviour, increase self-efficacy, and improve access to care for individuals with DD. According to Roll (2017), there are four strategies to achieve health promotion for people with DD: supporting a healthy lifestyle, which includes physical activity and diet; providing health education; involving supporters of people with DD, and being person-centered. These strategies were adopted by most interventions reviewed here.

Key elements to increase outcome of a health promotion drawn from this review include: greater use of theoretical frameworks to guide interventions, behaviour focused, greater inclusion of caregivers into program, the use of appropriate teaching strategies, the use of curriculum specifically designed for this target population, and continued support from staff. Some innovated approaches gleaned from this review are: targeting both individuals with DD and caregivers for your intervention; appointment of a health ambassador to organize health promoting activities for residents; creation of a study circle for caregivers to plan health promoting work, utilization of a standard mechanism for reinforcing health lifestyle behaviour, and the use of individuals with IDD as co-trainers in wellness programs.



## 3.0 Research Methods

#### 3.1 Research Setting

For convenience and feasibility, the pilot study was conducted mostly at the Options for Independent Living and Development (OFILD) residential site where the health and wellness hub is located. The individual interviews took place onsite in the health and wellness hub and the focus group occurred at a local community kitchen.

#### 3.2 Research Design

This project has been reviewed and approved by the Community Research Ethics Board. The study includes three distinct components:

- The design and development of an on-site health and wellness hub (herein after referred to as the Hub);
- 2) Piloting of the Hub with program participants; and
- The evaluation of the Hub by team leaders/support workers and program participants.

#### The Development of the Hub

An existing room with kitchen facility and adjacent space at the pilot site (OFILD) was renovated and used as the centralized Hub. The Hub was designed to function as a place where residents could get together for classes, socialization, and many other activities. New furniture, plants, lighting and other amenities

were added to make the space more welcoming. A variety of health promotion programs including nutrition education, cooking classes, life skills education series (i.e. laundry, shopping, budgeting, personal care, cooking), physical activity (yoga, tai chi, gym, swimming), and monthly social outing were offered to program participants over the 6-month pilot period. Other support services offered at the Hub included breakfast and evening meals, assistance with medications, blood glucose and blood pressure checking, foot care, coordination of DARTS for participants, and referrals to community-based treatments (e.g., dental, vision, psychiatric assessment). The Hub was open between programming and during regular Hub hours (Monday to Friday, 7:00-10:30 AM and 4:00-8:30 PM).

#### **Piloting of the Hub with Program Participants**

The purpose of the pilot is to determine whether program participants gain nutrition knowledge, life skills, levels of physical activity, and improving behaviours towards food choices after attending the wellness programs. A quantitative design consisting of the following questionnaires were used: i) pre/post nutrition knowledge questionnaires ii) pre/post cooking skills efficacy questionnaires ii) pre/post life skills efficacy questionnaires ii) pre/post life skills efficacy questionnaires iv) self-reported physical activity logbook The Data Collection Tools section provides a brief description for each of the questionnaires used.

Piloting of a Health and Wellness Hub for Adults with Developmental Disabilities 20

The pilot was six months long and the primary population was adults with developmental disabilities. Individuals recruited to take part in the pilot project were to agree to work on two or more healthy living objectives i.e. strengthen life skills, increase physical activity, improve food choices. Prior to the start of the program, participants met with their team leader to determine relevant personal goals, developed a program with specific short-term objectives, and support activities designed to achieve the objectives. The team leaders worked with their participants in the areas of health promotion activities and health behavior to affect overall changes in health and wellbeing. Whenever possible, team leaders acted as role models and took part in activities with participants to coach, empower, and facilitate attainment of goals.

The frequency and length of classes varied depending on the types of activities they sign up for. The programs were usually 4-5 weeks long and took place once a week. Each class lasted about 45 minutes except for the cooking classes which were 90 minutes long.

#### **Evaluation of the Hub**

The evaluation explored the perceptions of participants and support workers/team leaders regarding their experiences with and perspectives about the wellness hub and possible areas for improvement. Specifically, the methods involved the following categories of research participants:

#### (i) individual interviews with program participants

Participants who completed the health promotion activities trial run were asked to take part in an interview. The interview focused on their experiences with the program, likes and dislikes, satisfaction with the variety of activities being offered at the hub, and their suggestions on program delivery and services. A copy of the interview guide is included in Appendix 1. Each interview was 30 - 45 minutes long. All interviews were audio-taped and then typed out. With individual's permission, some direct quotations from the interview were used to enhance our understanding of the topic. Any direct quotations were anonymized so that the individual cannot be identified

#### (ii) focus groups with team leaders/support workers

Team leaders and support workers who were involved in the pilot project were invited to take part in a focus group meeting. The objectives of the focus group discussion were to assess the support workers/team leaders' perceptions about the wellness hub and challenges they encountered during program implementation, and to obtain input on program improvement and service delivery. The focus group meeting was 90 minutes long and was audio-taped; a note taker was present during the session. The focus group guide is included in Appendix 2.

### 3.3 Data Collection Tools

Below is a brief description for the data collection tools used in the study:

#### Nutrition Knowledge Questionnaire

The questionnaire (appendix 1) was developed based on the video content as well as on the information covered during the facilitated discussions. It consists of 20 questions varying in complexity. The choices are depicted in a picture format and minimum writing is required to complete the form.

#### Cooking Skills Efficacy Questionnaire

The questionnaire (appendix 2) contains 18 questions based on skills taught during the course. Each question includes two choices–"Yes" and "No". The questionnaire includes graphics to help participants understand the question being asked. No writing is required to complete the form.

#### Life Skills Questionnaire

The questionnaire (appendix 3) assesses participants' perceptions about their confidence in performing certain daily living activities by themselves such as laundry, shopping, self-care, budgeting, and the use of kitchen equipment. Each question includes two choices–"Yes" and "No". The questionnaire includes graphics to help participants understand the question being asked. No writing is required to complete the form.

#### Self Reported Physical Activity Log Sheet

Self-reported physical activity log sheets (appendix 4) were used for participants to record the type(s) of physical activity and the length of time they engaged in each of the activity. Graphics are used to depict different types of physical activities to choose from; in addition, a number is assigned for each activity. Participants were asked to write the number representing the exercise they did and select the duration of their exercise. The logbook was recorded every other day after the breakfast service and team leaders were present to provide assistance to participants who needed help filling out the log sheet.

#### 3.4 Data Analysis

Descriptive analysis (frequencies, percentages) was used to describe the data collected from the nutrition questionnaires. For analysis, each pre-and posttest was given a score based on 100 points. Pre- and posttest scores were compared to determine knowledge gain. For the cooking and life skills questionnaires, the total number of "yes" responses for each question was compared between pre-and posttest to determine gain in self-efficacy. For physical activity, frequency of physical activity from baseline data was compared to the average exercise frequency during the six-month pilot period.

For the qualitative data, a research assistant transcribed the individual interviews and the focus group discussions. Following transcription, responses from the 14 interviews were combined and summarized according to the specific questions in one document and the focus group in another. Emerging themes as well as recurrence of responses were identified from the two data sets. After several more reviews, the data were further refined.



## 4.0 Key Findings

### 4.1 Study Participants

#### Adults with Developmental Disabilities

Participants were recruited from OFILD. Sixteen adults, aged 39–70, with various levels of DD and mental health participated in the pilot study. The length of their residence at the Home (OFILD) ranges from 1 to 31 years. Three of the participants had a history of homelessness. Of the sixteen participants, 14 took part in the individual interviews. Two participants were unable to attend the interview as intended. One participant was hospitalized for an unexpected illness; the other participant was experiencing some personal issues.

#### Team Leaders and Support Workers

Six team leaders/support workers who were involved in the wellness hub took part in the focus group discussion. The group consisted of full time, parttime, and casual staff as well as program director and manager. These people provide assistance with daily living skill and/or support the planning, delivering and development of group based activities.

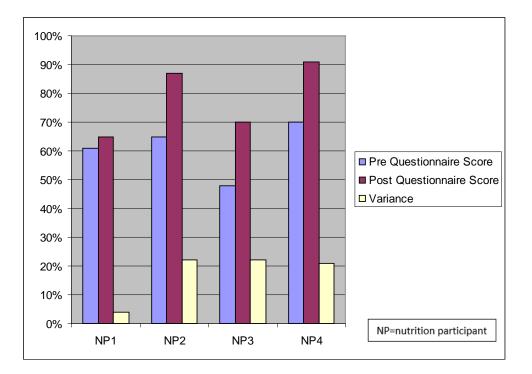
## **Results of Current Study**

## 4.2 Results of Participant Questionnaires

#### Nutrition Knowledge Questionnaires

Four adults with DD took part in a 5-week educational program led by a health educator. The education sessions included video viewing, followed by facilitated group discussion and workbook exercise. Pre- and posttests were used to measure knowledge gained from participating in the intervention. Figure 1 illustrates participants' pre- and posttest scores for the nutrition questionnaire. All participants improved their knowledge scores following the intervention. Of this total, one had a knowledge gain of 4% and three had a gain over 20%.

# Figure 1. Nutrition questionnaire pre- and posttest outcome for program participants.



#### **Cooking Self-Efficacy Questionnaires**

Six participants attended a 10-week cooking sessions facilitated by a Registered Dietitian. Of these participants, one had a career background as a cook and another had training in cooking and food safety. Each class was 90-minute long. Pictorial recipes with clear illustrations of preparation steps were used for the cooking program. Some participants were able to follow the recipe instructions all by themselves, others required more support. The pre/post test results show that five of the participants have increased cooking efficacy after the intervention. One participant, however, had a reduction in the cooking efficacy. Figure 2 shows the pre/post differences in the total number of "yes" responses for the cooking efficacy questionnaire among the program participants

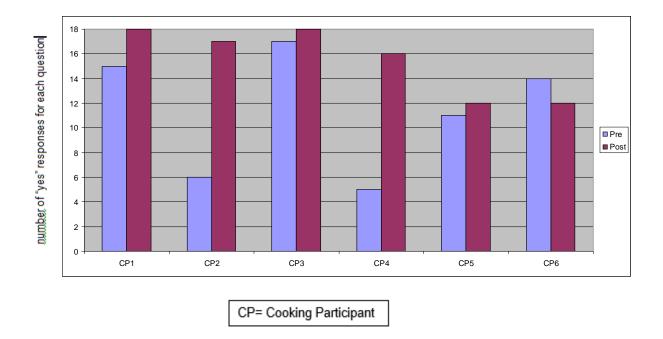


Figure 2. Summary of Pre/Post Responses for Cooking Efficacy Questions

#### Life Skills Questionnaires

Seven adults with DD took part in an 18 -week life skills program led by a support staff. During the program, participants learned to use various household equipment, proper cleaning of living room and kitchen, disposal of garbage, handling of household hazards, and development of good personal hygiene. To enhance the likelihood of skills transfer, each in-class session was followed by a hands-on practice period at the participant's living space. Figure 3 shows the pre and posttest results. Seventy-one percent (n=5) of participants felt more confident in their ability to perform the life skills taught in class after the intervention. There was no change in self-efficacy for two of the participants; both participants felt they had the same level of confidence in these life skills before and after the intervention.

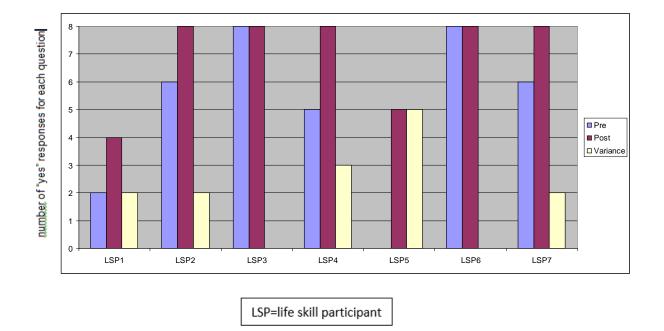
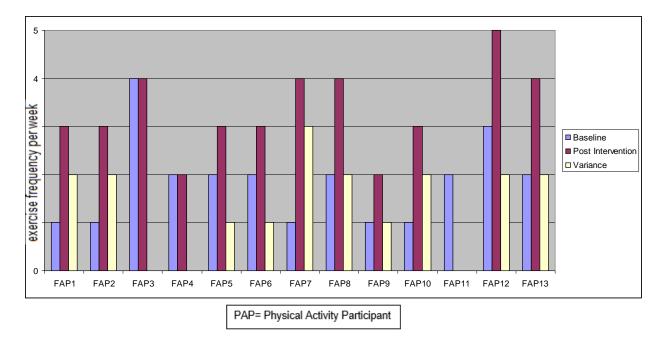


Figure 3. Summary of Pre/Post Responses for Life Skills Questionnaire

#### **Physical Activities Baseline and Log Sheets**

Thirteen adults with DD participated in various physical activities; among them, eight took part in structured fitness classes offered onsite and led by a fitness instructor. The fitness program was 4 months long and took place once a week with each class lasting for 50 minutes. Participants engaged in different physical activities including using hand weights, exercise bands, yoga, and qigong. Participants not enrolled in the structure classes got involved in walking or exercising at the onsite gym. Some participants swim regularly at the local community centres. When comparing the baseline exercise frequency data with post-intervention records, the majority of participants (80%) had an increase in their physical activity frequency; two participants had no change in their physical activity frequency. Assessment for one participant could not be completed due to absence of information in the log book. The results are illustrated in figure 4. Figure 4. Summary of Baseline and Post-Intervention Physical Activities Frequency



#### 4.3 Results of Participant Interviews and Focus Group Meeting

The results of the qualitative study identified the experiences and preferences of participants regarding the Hub. It also highlighted many positive aspects of the Hub and potential areas for improvements and long term sustainability. All study participants reported having a gratifying experience with the Hub; they felt that the Hub offers enough program varieties to choose from. The program participants particularly enjoyed the learning and socialization aspects of many activities such as breakfast services, skills building classes, and evening drop-in sessions. The team leaders reported that they observed a greater degree of bonding among the program participants than they were before.

Major themes drawn from the analysis of the transcripts from individual interviews and the focus group are summarized below.

#### Experiences of Participants with the Hub

Both respondent groups – participants and team leaders/support workers reported overall positive experiences with the Hub. The program participants described their personal involvement with the Hub as "enjoyable", "fun", "good", "fantastic", or "excellent". All team leaders/support workers were in agreement that the Hub was beneficial for everyone involved. One focus group participant (FGP) commented the following: "I think it was very positive for everybody around, for us individually and for the residents. We also had other residents that weren't part of the program that had asked to be in the program ....I think it was a win-win for everybody around" (FGP3)

When the participants were asked if there were any aspects about the Hub that they did not like, the majority of them indicated they were happy with everything. One team leader reported that she did not like the amount of paper work they had to complete for the pilot project. It was also pointed out that some program participants did not like or had difficulty to fill out the physical activity log sheet.

#### Participants' Views and Preferences toward the Hub

The team leaders/support workers felts that the Hub was a unique project that offered many social, learning, and growth opportunities. One support worker said,

"From what I've heard there's truly nothing like it in Hamilton for these type of clients. It has been a great opportunity for them and for us to learn and plan the next improvement". (FGP1)

Another team leader's comment reflected similar sentiment of the group,

"I thought it was a good learning opportunity, not just for the participants, but for myself as well in terms of learning how we can think about service improvements and trying to figure out ways to deliver assistance in a way that makes sense". (FGP2)

Both participant groups identified that breakfast service, the skills building and fitness classes, and the social outings as the favourite activities among the program participants. One program participant (PP) commented the following:

"The breakfasts were amazing, the healthy cooking class was amazing too because we learnt different recipes and learned how to cook healthy meals" (PP4)

#### Perceived Impact of Hub on Program Participants

There was a general consensus among the team leaders/support workers that the Hub brought people together. Many team leaders/support workers reported the close connections formed among the program participants they have observed.

"Well, what I liked was that it was bringing people together, and from there they would plan different social events and also uh, even plan things together outside of the Hub". (FGP4)

"I experienced the participants connecting with one another, which was really a good improvement. And I also experienced some of them making healthy choices and being more health conscious." (FGP6) A number of team leaders reported positive social and dietary behaviour changes they have observed for some program participants as the result of attending programs at the Hub.

"I don't know if were giving names, but M (resident) is one of many actually that really, I think engaged into it. He was one to stay in his room and not get out, now he's walking every day, he's eating a lot more healthier. Um, socially he has done a 360." (FGP2)

"One of the newer participants their family was quite impressed with the opportunity and commented on the improvements that they have seen in a relatively short amount of time, so they were quite impressed".

(FGP1)

#### **Challenges Experienced with Program Implementation and Delivery**

The team leaders/support workers identified a number of challenges they experienced during the pilot phase. These included internet issues, limited program space, program coordination and scheduling, and workload. The frequent issues with internet in the Hub resulted a delay in computer training for program participants. It was felt that the Hub space is not large enough to accommodate some activities such as yoga and fitness classes. There was no coordination in terms of allocated time for team leaders to meet and spend time with their participants to review their progress. The cooking classes were scheduled to close to the meal time which negatively impacted the program participants and the organization of classes. There was a general sense from some team leaders/support workers that they were overwhelmed with the workload.

"So it was just sort of hard to be able to manage everything, it would have been nice to have the extra staff or have a time that you could just go and just do that whereas, we didn't really have that luxury, we just had to do it when we had downtime". (FGP5)

"So there were circumstances where by we didn't have the optimal amount of help, so we improvised, but sometimes those uh, factors are beyond your control". (FGP3)

Also, It was mentioned that although program calendar was available in the participant's room, many of them required constant reminders and sometimes physical help to attend program on time. One support worker said,

"Well one time, one of the residents just said she didn't want to come at all and then another resident had come late, so at that point it was finished but we were able to give the participant some food to take with them". (FGP1)

### **Potential Involvement of Program Participants**

During the pilot phase, the program participants were not involved in any program tasks such as meal services, with the exception of one individual who helped out with breakfast preparation. It was believed that more participants could be helping out as they gained knowledge and skills. When the program participants were asked what they could do if they could help out at the Hub, they all indicated that that they could be involved in some ways during the meal times such as food preparation and all aspects of cleaning.

### Areas for Improvement and Long-Term Sustainability

The team leaders/support workers identified a number of areas for improvement and for program sustainability, specifically, in areas related to communication, scheduling, support for program participants, involvement of other potential partners, and leveraging of existing community resources.

The importance of ongoing communication among the team leaders regarding all aspects of program activities and progress of participants was highlighted. Regular team meetings and informal dialogues could help provide updates to each other. Some support workers also pointed out the need to schedule regular time for team leaders to meet with participants to discuss progress, needs or issues.

"I think it would have been nice if we had some designated time put aside each week so that we could meet with our participants". (FGP4)

To help participants apply life skills they learned during the program, the Home should offer them additional opportunities to practice their skills such as laundry, cooking or cleaning.

In terms of sustaining the program, it will be necessary to leverage existing resources, reaching out family members, volunteers, strengthening past partnerships, and reaching out to more potential community partners such as Mohawk College, McMaster University, Hamilton Public Health, local churches, recreation centres, YWCA, to name just a few.

Health 3/4 & Wellness

## 5. Discussion

The results of both quantitative and qualitative data showed that the health and wellness hub made a positive impact on the program participants as well as the service provider. The program participants enjoyed the learning and social opportunities that the Hub offered and were pleased with the variety of programs and services that were available to them. The majority of participants felt more confident about their ability to cook and perform basic daily living skills. They have also engaged in physical activity more often.

It should be noted that participants signed up for classes based on their interest rather than their need to learn particular skills. For example, in the cooking classes, two of the participants already knew how to cook prior to the program; hence, there was only a small change in their pre/posttest results. Those who attended the nutrition education program have increased their knowledge about healthy eating. Although the duration of the nutrition program was short, video lessons and pictorial workbooks were well received by the participants; the visuals materials facilitated learning and worked very well with this group of participants. It would be interesting to know if any information is retained 3-6 months post intervention.

The team leaders/support workers expressed their appreciation for the opportunity to be involved in the pilot project and to support the program participants in adapting a healthier lifestyle.

The challenges identified in terms of space, scheduling, and staffing are not uncommon when implementing a healthy promotion program for this target population (DerAnanian et al, 2012). With regards to limited space to be used as a Wellness Hub within a facility, there is no easy solution. The alternative might be looking for a space in the community, this, however, will not be as easily accessible as having an onsite Hub for the participants due to their travel requirements. There might also be a cost associated with the use of the community space. Time constraints of program staff, scheduling issues have been shown to create barriers to successful program implementation (Spassiani, et al, 2015). The use of students, volunteers, family members/caregivers and program participants may provide some relief for the staff while offering learning opportunities and meaning work for others.

To sustain the program, the team leaders/support workers have identified potential community agencies and partners for support and collaboration. Having a commitment from all stakeholders including program participants, family members, caregivers, and staff members is important for the success of the intervention (Spassiani, 2015). Organizational commitment and the utilization of the existing resources would be critical to carry on and sustain the initiative. Additionally, providing individuals with DD additional opportunities to practice what they learned from the program as well as ongoing support and reinforcing healthy lifestyle habits will help knowledge transferability and increase the likelihood of sustained healthy behaviours.

## 6. Limitations of the Study

There are some limitations to the present study. First, most participants with DD had difficulty in answering open-ended questions during the interview; examples of possible responses were used as a means to elicit clarification. This may have introduced response biases. Second, the reliance on self-report of exercise duration and frequency. Individuals with DD often have difficulty with recalling and the concepts of quantity and time (Ewing, et al, 2004), so their assessment of exercise frequency and duration may not reflect actual exercise time. Third, the team leaders and support workers in the focus group came from the same organization; thus, the study would have been strengthened with representation from other agencies.

## 7. Conclusion

The goal of this project was to determine the impact of an onsite health and wellness hub in supportive living arrangements on the residents and explore the team leaders'/support workers' and program participants' views about the Hub. The current study has shown that an on-site health and wellness hub that offers coordinated services and a variety of health promotion activities can assist individuals with DD to adopt a healthy lifestyle, develop skills, achieve goals, develop and strengthen positive relationship with friends, and participate in meaningful activities/opportunities such as social activities and education and skills building.

The pilot project also provides some ideas for organizations who may wish to adopt or incorporate some aspects of the model into their existing program for this population, for example, leveraging existing resources, collaboration with other community partners, and involving program participants.

Implementation of any health promoting program requires resources, commitment from the organization, and capacity to sustain consistent support for the planned project. Other strategies for enabling organizational capacity for promoting healthy lifestyle behaviours for people with DD include: staff finding intrinsic and extrinsic rewards for supporting healthy behaviour i.e. observing residents eating healthier, certificates or incentives, and strengthening "helping relationships" within the organization and external environment i.e. management support and flexibility, availability of training opportunities (O'Leary, et al, 2017). Wellness initiatives play a vital role in maintaining and improving the health, function, and participation of people with DD; it can also help prevent the onset of many chronic diseases and manage their illness should they develop a chronic health condition (Taggart, 2018). The availability of this type of wellness program may help address housing instability and many health concerns facing this population. We note that all participants remain stable and housed at the conclusion of the study. The organization has continued to provide some aspects of the Hub activities in an ongoing effort to learn, adapt, and build greater capacity as it pursues additional positive outcomes for its residents.



## References

Anderson, LL., Humphries, K., McDermott, S., Marks, B., Sisirak & Larson, S. (2013). The State of the Science of Health and Wellness for Adults With Intellectual and Developmental Disabilities. Intellect Dev Disabil. 51(5). 385-398

Bach, M. (2011). Barriers to adequate housing for people with intellectual disabilities. Retrieved from

http://www.acto.ca/assets/files/cases/Afd.%20of%20M%20BACH,%20Exe%20Vi ce%20President,%20Canadian%20Association%20Of%20Community%20Living %20-%20FINAL.pdf

Backer, T. E., & Howard, E. A. (2007). Cognitive impairments and the prevention of homelessness: Research and practice review. J Prim Prev, 28(3-4), 375-388.

Bazzano, AT., Zeldin, AS; Shihady, IR; & Garro, NM. (2009). The Healthy Lifestyle Change Program: A pilot of a community-based health promotion intervention for adults with developmental disabilities. Am J Prev Med, 37(6S1), 201- 208.

Bergstrom, H., Hagstromer, M., Hagberg Jc, & Elinder, SH. (2013). A multicomponent universal intervention to improve diet and physical activity among adults with intellectual disabilities in community residences: A cluster randomized controlled trial. Res Dev Disabil, 34 (2013) 3847–3857.

DerAnanian C., Desai P., Smith-Ray R., Seymour R. B. & Hughes S. (2012) Perceived versus actual factors associated with adoption and maintenance of an evidence-based physical activity program. Transl Behav Med, 2, 209–217.

Durbin, A., Isaacs, B., Mauer-Vakil, D., Connelly, J., Steer, L., Roy, S. & Stergiopoulos, V. (2018). Intellectual disability and homelessness: a synthesis of

the literature and discussion of how supportive housing can support wellness for people with intellectual disability. Current Developmental Disorders Reports. 5:125–131.

Dunkley, AJ., Tyrer, T., Doherty, Y, Martin-Stacey, L, Patel, N, Spong R, et al. (2017) Development of a multi-component lifestyle intervention for preventing type 2 diabetes and cardiovascular risk factors in adults with intellectual disabilities. J. Public Health.1–10.

Ewing, G., McDemott., Thomas-Koger, M., Whitner, W. & Pierce, K. (2004). Evaluation of a cardiovascular health program for participants with mental Retardation and normal learners. Health Educ Behav. 31 (1): 77-87.

Heller, T., Hsieh, K., & Rimmer, J. H. (2004). Attitudinal and psychosocial outcomes of a fitness and health education program on adults with Down syndrome. Am J Ment Retard;109(2):175-85.

Johnson, S. (2016). The Impact of Housing and Homelessness on Persons with Developmental Disabilities: Connecting the Literature. Retrieved from: http://tdsa.ca/wp-content/uploads/2017/09/Lit-Review-Developmental-Disabilitiesand-Housing.pdf

McDermotta, s., Whitner, W., Thomas-Kogerb, M., Mann, JR., Clarkson, BJ., Barnes, TL., et al. (2012). An efficacy trial of 'Steps to Your Health', a health promotion programme for adults with intellectual disability. Health Educ. J, 71(3) 278–290.

Montana Disability and Health Program. The wellness club. Retrieved from: http://mtdh.ruralinstitute.umt.edu/?page\_id=371 O'Leary,L., Taggart, L., & Cousins, W. (2018). Healthy lifestyle behaviours for people with intellectual disabilities: An exploration of organizational barriers and enablers. J Appl Res Intellect Disabil. Suppl 1:122-135.

Ontario Human Rights Commission. Retrieved from: http://www.ohrc.on.ca/en/right-home-report-consultation-human-rights-andrental-housing-ontario/housing-human-right).

Roll, AE. (2018). Health promotion for people with intellectual disabilities – A concept analysis. Scand J Caring Sci; 2018; 32; 422–429

Scott, HM, Havercamp. (2016). Systematic review of health promotion programs focused on behavioral changes for people with intellectual disability Intellect Dev Disabil, 54(1), 63–76.

Spassiani, NA., Harris, SP, & Hammel, J. (2015). Exploring how knowledge translation can improve sustainability of community-based health initiatives for people with intellectual/ developmental disabilities. JARID, 29, 433–444.

Sundblom, E., Bergstrom, & Ellinder, LS.(2015). Understanding the implementation process of a multi-component health promotion intervention for adults with intellectual disabilities in Sweden. JARID, 28, 296–306.

Taggart, L., Truesdale, M., Dunkley, A., House, A., & Russell, AM. (2018). Health promotion and wellness initiatives targeting chronic disease prevention and management for adults with intellectual and developmental disabilities: recent advancements in type 2 diabetes. Curr Dev Disord Rep (2018) 5:132–142.

## Appendix 1. Interview Guide (p.1)

#### Interview Guide for Participants with Developmental Disabilities

### Participants

#### Introduction

"Hello, my name is Chwen Binkley, I am the lead person for this study project. I am going to ask you some questions about what you think about the *Health and Wellness Hub* and your experience with the types of services and programs you have attended. You don't have to answer any question if you don't want to, and I'll stop anytime you want me to. There is no right or wrong answer. I will tape our interview as my notes if you are ok with it. Ms. X (support worker) is here to assist us in this interview. Ms. X will not be answering the questions – I want to hear your answers."

#### Let's start with some questions about your experiences

- What was your overall experience with the Wellness Hub? Probe: Was it fun, did you learn anything? Give me some examples of good and not-so-good experiences you have had?
- Do you feel that the programs and services offered at the Hub help you in any way personally?
   Probe: Did they help you eat healthier? stay active? socialize with people more, or they did not help you much..etc.
- What did you like about the Wellness Hub? Probe: types of programs, activities, social events, snacks.
- What didn't you like about the Wellness Hub? Probe: types of program, activities, social events

#### Now I have some questions about what you think about the Hub

 Do you think there were enough programs/activities for you to choose from?

Probe: Were there any other services or programs you would have liked to see being offered there?

## Interview Guide (p. 2)

- Are there any other services/programs/activities you think the Hub should be offering to help you stay healthy? Probe: Think of 2-3 things you would like to see being offered there e.g., birthday parties, taste testing, board games, reading club, more social and recreational events.
- How can we make the Hub a better and more enjoyable place for you? Probe: If there is one thing you like to change about the Hub, what would that be? E.g., furniture, atmosphere, healthy snacks, regular events..)
- If you have an opportunity to help out at the Hub, what kind of things do you think you can do?
   Probe: e.g. wiping tables, cleaning floors, wash dishes, shopping for food... etc.
- Is there anything else you would like to share with us?

## Appendix 2. Focus Group Guide (p.1)

### Piloting of a Health andWellness Hub for Adults with Developmental Disabilities

Introductory Script and Questions for the Focus Group

### Team Leaders/Support workers

#### 1. Welcome & Introductions

I would like to welcome and thank you for participating today. My name is Chwen Binkley, your facilitator and this is \_\_\_\_\_, the Note Taker. {Everyone introduces herself/himself, if necessary}

The purpose of the focus group today is to talk about your experience with the *Health* and *Wellness Hub*, your perceptions about the *Hub* and potential areas for improvement to make it more useful and enjoyable for the participants. We want to hear your views about what you have experienced and observed during the pilot project and options for the future. The information obtained will provide important input into improvement and sustainability of the hub for the clients.

This session will last about 90 minutes. Please feel free to get up anytime for refreshments and snacks.

#### 2. Privacy

The Note Taker will be using a computer to record observations and take notes. She will not be participating in the discussion. A tape recorder will be used to capture our discussion and to ensure the accuracy of content is reflected in the notes.

As participants, your privacy is important to us. We ask that all comments made during the discussion be kept confidential within the group. In our reports, comments will be kept anonymous and your name will not be used in any reports. The results will be included in the project report and may be published in academic journals as well.

#### 3. Ground Rules

We have posted some ground rules on the wall. Anything missing that we should add?

- Participate actively in discussion
- Respect each other
- Provide feedback with an open mind
- Respect confidentiality

### Focus Group Guide (p.2)

#### 4. Focus Group Questions

Our discussion will focus on 3 areas including your experiences with the *Wellness Hub*, your perceptions about the usefulness of the *Hub*, and potential areas for improvement. If there are no more questions, let us begin.

#### Experiences with the Health and Wellness Hub

- What is your overall experience with the Hub?
- What did you like about the Hub?
- What didn't you like about the Hub?
- 4) Did you experience any barriers or challenges when helping program participants to access the services and programs? Please describe.
- Did the centralized Wellness Hub impact your work routine in any way? Please describe.
- 6) Did you receive enough support and training to help with the implementation and delivery of services and programs?

#### Perceptions about the Health and Wellness Hub

- What are your views about the organization, delivery and implementation of the services and program activities offered at the *Hub*? What worked well? What didn't work? Were there any processes that should have been in place?
- 2) Do you think the Hub offer the kinds of services and program activities that meet the participants' needs? If not, what kinds of services or programs should be offered?
- 3) What kind of services and program activities did participants enjoy the most? Were there any activities they didn't seem to enjoy?
- 4) What are your views about the usefulness of the Hub? Do you think the participants like it? What were some of the comments you heard from the participants?
- Have you observed any changes in participants' behaviours e.g., increased participation of social events, increased physical active, appeared happier...etc.

## Focus Group Guide (p.3)

### Areas for Improvement and Sustainability

- Do you have any suggestions to improve the organization, delivery, and implementation of the Wellness Hub?
- 2) Do you have any suggestions for the layout/design of the facility? What suggestions do you have for the design of the hub? Are there any modifications that you would recommend?
- 3) What kind of challenges do you foresee in maintaining the Hub? What are some of your suggestions for overcoming these challenges?
- 4) What kind of resources and support do you think we need to continue with the Hub after the project is finished?
- 5) In terms of participants and stakeholders/partners, how do you think they should be involved?

### 5. Member Check

To summarize our discussion, we talked about \_\_\_\_\_(main points). Did I capture everyone's points? Does anyone have anything to add?

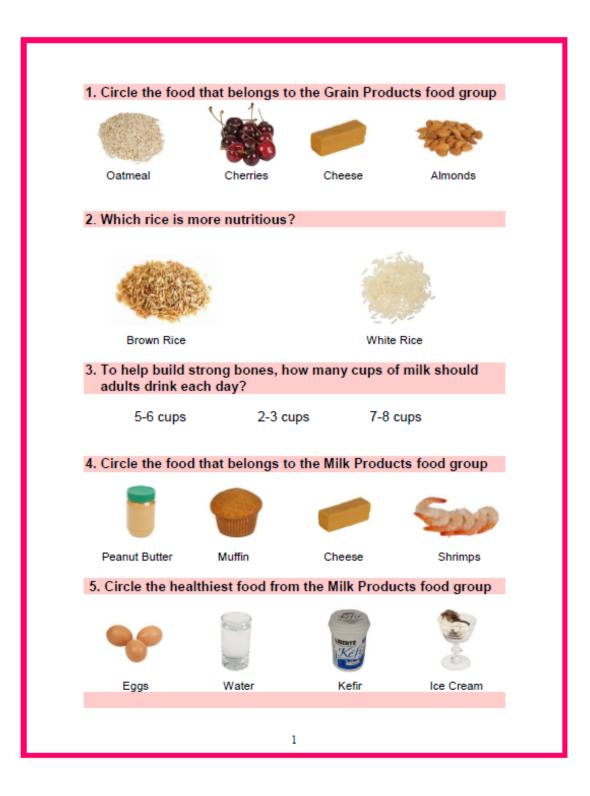
### 6. Demographic Data Collection

The note-taker will distribute a short questionnaire for you to complete. We would appreciate that you take a few minutes to fill out the form.

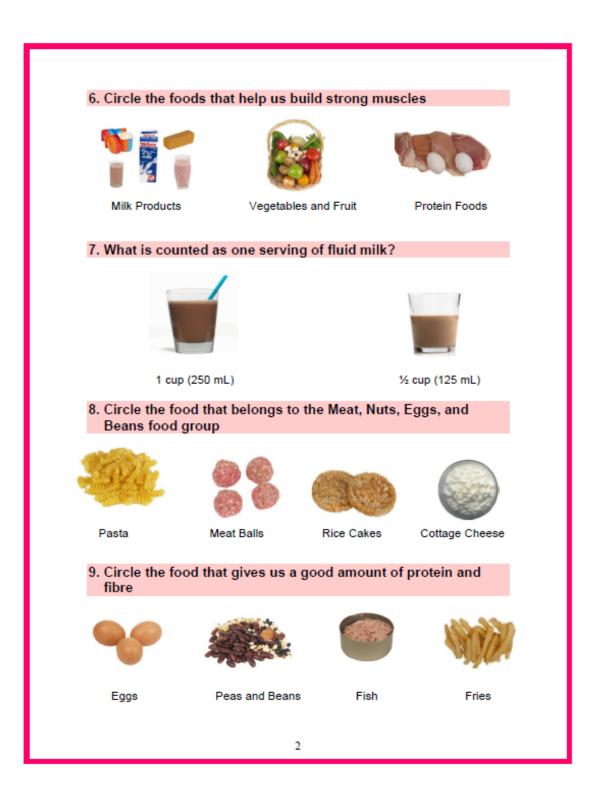
#### 7. Closing

Thank you again for your participation.

# **Appendix 3. Nutrition Knowledge Questionnaire (p.1)**



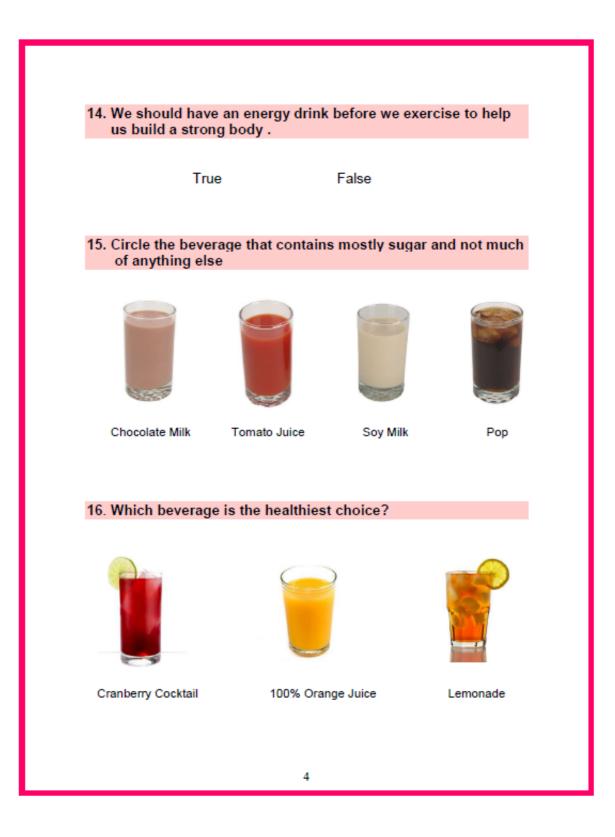
# **Nutrition Knowledge Questionnaire (p.2)**



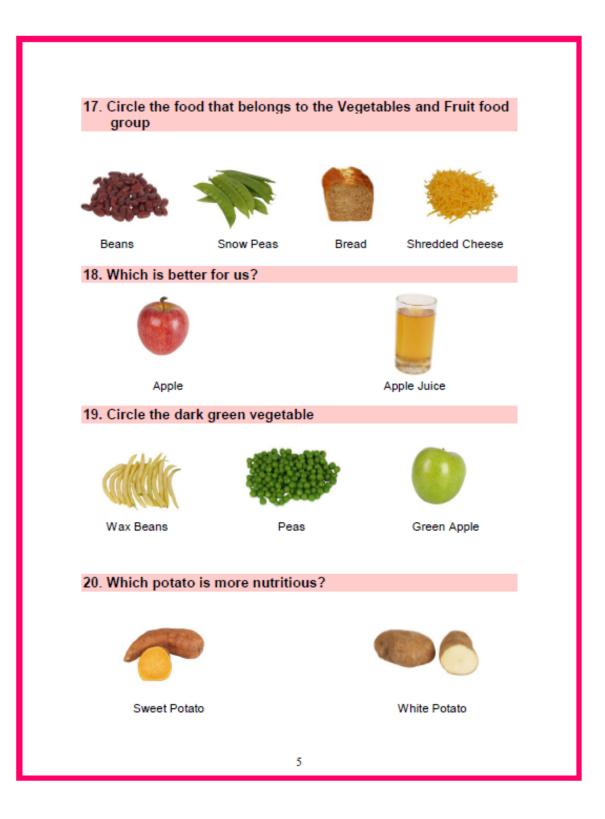
# **Nutrition Knowledge Questionnaire (p.3)**



# Nutrition Knowledge Questionnaire (p.4)



# **Nutrition Knowledge Questionnaire (p.5)**



# Appendix 4. Cooking Skills Questionnaire (p.1)

### **Cooking Skills Questionnaire**

Participant ID: \_\_\_\_\_

Do you think you can	Visual	Yes	No
<ol> <li>follow directions in a recipe all by yourself</li> </ol>			
2. measure ingredients all by yourself			
3. use the microwave oven all by yourself			
4. use the oven all by yourself	đ		
5. use the stove top all by yourself	ALC: NO DECEMBER OF		
<ol> <li>use small kitchen tools</li> <li>e.g. peeler, can opener all by yourself</li> </ol>			
7. handle knives safely all by yourself			
8. keep food clean and safe all by yourself	<u> </u>		

# **Cooking Skills Questionnaire (p.2)**

How sure are you that you can	Visual	Yes	No
9. make a salad all by yourself	Ś		
<ol> <li>prepare a simple meal such as spaghetti all by yourself</li> </ol>			
<ol> <li>prepare a healthy snack all by yourself</li> </ol>			
12. cut up vegetables all by yourself			
13. try new foods all by yourself			
<ol> <li>choose healthy food all by yourself</li> </ol>	۲		
15. get groceries all by yourself	) I I I I I I I I I I I I I I I I I I I		
16. set the table all by yourself	<u>lo</u> li		
17. know about proper table manners	Ĩ		
<ol> <li>clean up dirty dishes all by yourself</li> </ol>			

# **Appendix 5. Life Skills Questionnaire**

### Life Skills Questionnaire

Participant ID: \_\_\_\_\_

Do you think you can	Visual	Yes	No
1. use a dishwasher all by yourself			
2. use a laundry machine to wash your dirty clothes			
<ol> <li>use the microwave safely all by yourself</li> </ol>			
<ol> <li>clean your room properly all by yourself</li> </ol>	<b>ب</b> ل		
5. clean the kitchen properly all by yourself			
<ol> <li>handle garbage disposal and recycling properly all by yourself</li> </ol>	<b>F</b>		
<ol> <li>handle householdhazards properly all by yourself</li> </ol>			
8. maintain good personal hygiene all by yourself			

# **Appendix 6. Physical Activity Log Sheet**

# My Physical Activity Log Sheet

Participant ID:	Week of:
l'alterpaire ibi	Week of

Day	Physical Activity You Did Write down the number under the picture for the activity you did	Length of Time You Perform the Activity Put a check mark (🗸 ) underneath the number of minutes in the bar graph				
Mon		<30	30	45	60	>60
Tue		<30	30	45	60	>60
Wed		<30	30	45	60	>60
Thur		<30	30	45	60	>60
Fri		<30	30	45	60	>60
Sat		<30	30	45	60	>60
Sun		<30	30	45	60	>60

