

Preface

Health Matters: The Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities is based on the successful outcomes of the innovative Health Promotion Program for Adults with Developmental Disabilities at the University of Illinois at Chicago (UIC), a 12-week exercise program that includes exercise, nutrition, and health education components. The goals of the program are to 1) improve fitness, 2) increase knowledge about healthy lifestyles, and 3) teach family, staff, and friends how to support participants to achieve these goals.

The benefits of health promotion activities have been well-documented for the general population. However, individuals with developmental disabilities are often not included in health promotion activities. For people with disabilities, changes in lifestyle and environmental conditions may have the same potential to improve physical, mental, and social functioning, and prevent the onset of lifestyle-related conditions, as they do in the general population. Thus, health promotion programs designed for adults with disabilities are necessary.

In order to better understand ways to promote healthy lifestyles among adults with developmental disabilities, this program has been evaluated by several research projects since 1998. They have been conducted at UIC in the Department of Disability and Human Development by the Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTCADD), Center on Health Promotion for Persons with Disabilities (CHP), and the UIC Midwest Roybal Center for Health Promotion and Behavior Change. Funding has been provided by the National Institute on Disability and Rehabilitation Research (NIDRR), Center for Disease Control and Prevention, National Institute on Aging, and The Retirement Research Foundation. The Principal Investigators for the UIC Health Promotion Program for Adults with Developmental Disabilities are Tamar Heller, Ph.D., Beth Marks, RN, Ph.D., and James H. Rimmer, Ph.D.

Research participants enrolled in both the center-based (1998–2003) and the community-based (2003–present) UIC Health Promotion Program for Adults with Developmental Disabilities participated in a comprehensive program consisting of exercise activities, nutrition and cooking classes, and health education classes with peer support. The classes consisted of the following activities:

1. The exercise classes included 1 hour of physical activity 3 days per week to improve fitness. Emphasis was placed on flexibility, cardiovascular endurance, balance, and muscle strength. Participants were taught how to properly use the equipment and exercise safely.
2. The nutrition and cooking classes were held three times per week for 1 hour. The lessons consisted of tips on healthy eating and food preparation, examination of eating routines and food labels, shopping tips, and selecting healthy foods from restaurant menus.
3. The health education classes met 3 days per week for 1 hour. The lessons consisted of activities helping participants to understand their attitudes toward health, exercise and

food; find exercises that they like to do and set goals; gain skills and knowledge about exercises and healthy eating; support each other during the course of the class; and identify places in their community where they can exercise regularly.

The center-based UIC Health Promotion Program for Adults with Developmental Disabilities was tested on four groups of 32 participants from six different vocational and residential agencies in Illinois (Heller, Hsieh, & Rimmer, 2004; Rimmer, Heller, Wang, & Valerio, 2004). The results demonstrated the following:

- Greater life satisfaction and less depression
- Increased exercise knowledge
- More positive attitudes toward exercise
- Increased confidence in ability to exercise
- Fewer barriers preventing participants from exercising
- Improved cardiovascular fitness
- Increased muscle strength and endurance

The community-based UIC Health Promotion Program for Adults with Developmental Disabilities is one of the first studies to examine the effectiveness of community-based health promotion programs to improve health and well-being of adults with intellectual and developmental disabilities (I/DD). This research study is documenting the effectiveness of direct support staff in community-based agencies (CBAs) in teaching adults aging with I/DD to be more physically active and eat healthier foods in their homes and workplaces. Agency staff were given 6–8 hours of training on starting a tailored 12-week physical activity and health education program personalized to their clients' needs using this curriculum. The community-based UIC Health Promotion Program for Adults with Developmental Disabilities was tested on four groups of 44 participants from four different vocational and residential agencies in Illinois and New Mexico. Results found significant changes in psychosocial health status, including less perceived pain, increased self-efficacy, and increased social/environmental supports. Although not statistically significant, participants in the 12-week program had increased self-rated general health status, higher life satisfaction, less barriers to exercise, and greater exercise outcome expectations following the 12-week program.

Staff participants who received the 6-hour Health Promotion Train-the-Trainer Program immediately prior to teaching the Health Promotion Program to adults with I/DD also showed significant changes in their psychosocial health status, including an increase in vitality and energy, less perceived pain, and increased exercise outcome expectations. Although not statistically significant, staff who received the training had increased self-rated general health status, improved psychological well-being, fewer exercise barriers, and greater self-efficacy to exercise regularly.

CURRICULUM PREMISES

The following premises are incorporated in the Exercise and Nutrition Health Education Curriculum:

- People with disabilities have a right to receive education and services that promote their health

- People can contribute to their own well-being by becoming knowledgeable about their health and health resources and by becoming active participants in health promotion activities
- Health promotion is not a form of social control but must be based on the needs and lifestyle preferences of individuals
- Support from caregivers and increased access to exercise activities promote exercise adherence.

The curriculum incorporates the following concepts that affect a participant's ability to change health behaviors: self-efficacy (Bandura, 1982, 1986), social support (including caregiver support), self-advocacy, choice-making, and leadership development. This builds on the RRTCADD's *Person-Centered Planning for Later Life: A Curriculum for Adults with Mental Retardation* (Sutton, Heller, Sterns, Factor, & Miklos, 1993) and *Making Choices as We Age: A Peer Training Program* (Heller, Preston, Nelis, Pederson, & Brown, 1995). An emphasis is placed on knowledge related to the benefits of exercise and good nutrition, available exercise and nutrition options in the community, personal choices regarding one's preferred lifestyle, and support from friends and relatives.

The curriculum was originally developed as a 12-week program with three 1-hour lessons per week. Each lesson covers a specific topic. The lessons are designed to build on each other, with some intentional overlap. This allows participants to continuously review material throughout the program.

The format of the curriculum encourages you to reproduce the parts you need to teach a specific lesson. In addition, a CD-ROM with color versions of the participant handouts and instructor references that accompany each lesson is available in the back of the book. We encourage duplication of the handouts and worksheets so that each participant can make a Personalized Notebook. Each lesson contains a facilitator script and references, along with the appropriate participant handouts and instructor references.

CURRICULUM DESIGN

Health Matters is based on the five stages of change in the Transtheoretical Model of Change—precontemplation, contemplation, preparation, action, and maintenance (Prochaska & DiClemente, 1992; Prochaska et al., 1994). In using this model, behavior change can be seen as a cyclical process rather than a linear process. As we work with people, we may see them going through these five stages at different rates. In fact, people often move back and forth between stages a number of times before they maintain their behavior change goal. In addition, people use different processes (or activities) to move from one stage of change to another, so it's important to target the “right” activity (processes) at the “right” time (stages).

Each stage is part of a continuum of readiness to change and includes specific topics designed to provide participants with options for changing their behavior. The five units in this curriculum incorporate the five stages of change. The model in Figure 1.1 on page 7 provides a visual representation of the five stages of change that are used in each of the units.

Unit 1 *Precontemplation Stage*—People are often unaware or under-aware of the need to change their behavior. The lessons focus on increasing the participants' understanding of health, exercise, and nutrition, along with making decisions about one's health.

- Unit 2 *Contemplation Stage*—People are aware that they should change their behavior and are seriously thinking about change but have not made a commitment to take action. In this section, participants consider lifestyle change and assess their exercise and nutrition behaviors.
- Unit 3 *Preparation Stage*—People are ready to take action and change a specific behavior. Classes focus on setting goals and examining barriers and influences that may affect people’s ability to exercise or eat a more nutritious diet.
- Unit 4 *Action Stage*—People are taking action and have changed their behavior(s). Participants are exercising and trying to include healthy foods in their diets. Classes focus on reinforcing new behaviors to maintain their exercise and nutrition goals.
- Unit 5 *Maintenance Stage*—People are considering ways to prevent relapse. Classes focus on reviewing what participants have learned and different ways to maintain their program. After the 12-week structured program of classes aimed at teaching and supporting people to feel more confident to engage in regular physical activity and make healthy food choices, people are encouraged to continue with classes as a part of lifelong learning. The Lifelong Learning Series in Appendix A features 22 lessons developed with participants in the UIC Health Promotion Program to compliment the 36 lessons that make up the core program to sustain long-term adoption of healthy lifestyles.

USING THE CURRICULUM

Starting Your Exercise and Nutrition Health Education Program

- Who** People with intellectual and developmental disabilities
- What** Health promotion program including exercise and nutrition education classes. See Appendix B for a list of common abbreviations and a glossary of terms used throughout the curriculum.
- Where** School, home, work, or community activity center
- When** Morning, afternoon, or early evening
- Size** 6–10 participants
- How** We recommend having at least two facilitators for the classes.
- The curriculum was developed as a 12-week program with three 1-hour lessons per week. Its design encourages trainers to customize the program for each trainee.
- Health education lessons may be enhanced by adding exercise and/or cooking activities.
- The curriculum includes various activities that can be modified to fit your teaching style and the needs of your participants. After the program is over, people can begin or continue doing activities that they tried during the course of the health education program.
- We recommend using parts of the curriculum to provide health education for caregivers and other support persons.

Tips for Starting an Exercise Activity Program

An exercise program should include a variety of activities that people enjoy doing (Rimmer, 2000). For example, on Monday, Wednesday, and Friday you may want to walk briskly for 30 minutes, lift weights for 20 minutes, and do flexibility exercises for 10 minutes. Riding a stationary bike, swimming, dancing, or doing an aerobic video can be substituted for walking. See Appendix C for sample exercise workouts that include the necessary components of an exercise program. Prior to starting an exercise program, you should consider the following steps:

- Step 1 Participants in the class need an okay from a health care provider (Rimmer, 2009). Make sure that people can safely begin exercising and will not aggravate any existing health conditions by regular exercise activity. The health care provider may recommend specific tests depending on the person's age and physical condition to determine any limitations in doing physical activities.
- Step 2 Encourage participants to do physical activities throughout the day. Incorporate physical activity into daily routines throughout the day. When added to a structured exercise program, this can increase a person's fitness level and consume more calories, if he or she is trying to lose weight (e.g., don't use a remote control device, use stairs instead of elevators, do stretching exercises while watching TV).
- Step 3 Choose the right program. Find an activity that fits the needs and interests of the individuals in the class. Make sure that the activity is accessible for all or most of the class. See Appendix D for strategies that can be used as you develop your health promotion program.
- Step 4 Teach participants to exercise a minimum of 3 days per week for at least 30 minutes.
- Step 5 Keep the program fun and rewarding. People must have fun doing the exercise activity in order to continue with their exercise program. Expose people to a variety of activities that they can do with their friends and family members or by themselves.
- Step 6 Foster fitness among staff and caregivers. People are more likely to engage in exercise activities if they see people around them participating in fitness programs.

Teaching Strategies

The teaching strategies used throughout the curriculum are characterized by processes of choice, self-determination, self-efficacy, self-advocacy, rights and responsibility. Implementation emphasizes two primary concepts based on primary health care: 1) maximum individual involvement in the planning and implementation of exercise and nutrition goals and 2) health promotive rather than curative activities.

In addition, strategies from *Primary Health Care Curriculum Grade K–8 for Urban School Children* (McElmurry, Newcomb, Lowe, & Misner, 1995), including problem-solving techniques, conflict resolution, and role playing, are used to teach the curriculum. These strategies may be used to facilitate the learning process in each of the classes depending on the group and the individual style of the instructor. They include the following:

1. *Problem solving* is a strategy that is not directly addressed in the curriculum but is recommended for the facilitator as an underlying approach in each of the lessons (McElmurry et al., 1995). The problem-solving or decision-making approach provides participants with the skills and attitudes necessary to become lifelong learners. In order for problem solving to work in the classroom, the facilitator needs to do the following:
 - Have objectives that can be accomplished through the use of the process
 - Set the tone for the progress of the class by ensuring that participants are relaxed and the atmosphere is calm, nonthreatening, and nonjudgmental
 - Practice the principles and reinforce them with the participants at every opportunity
2. *Conflict resolution* is another strategy used throughout the curriculum as an underlying approach to teaching the content of each lesson. Conflict is defined as a clash of opinions, needs, or wants between individuals or groups (McElmurry et al., 1995). The result of a conflict may be positive or negative. When handled correctly, conflict can lead to growth within individuals or groups. It can help participants see that their needs and wants may be different from those of others and that this may result in disagreements. Conflict resolution can help people understand that the person with whom they disagree has the right to his or her own needs and wants. Moreover, each person has the right to be accepted regardless of his or her point of view. Lastly, conflict resolution can help participants identify positive ways of resolving conflict such as demonstrating a willingness to discuss the situation to clarify the problem and trying to search for a solution that is agreeable to each person.
3. *Role playing* may also be used by the facilitator to teach the curriculum content. The reason for using role playing is to introduce the content through the participants' actual health experiences (McElmurry et al., 1995). Initially, ask for volunteers or select participants who are likely to talk and role play and who can follow general instructions related to the role or situation for the first few lessons. In the role playing exercises, have participants look for specific points or identify with the feelings of the actor in the role play. Participants' interest, involvement, and learning is easier when they have a specific task. Encourage people to express themselves freely. Address all remarks to the "characters" by name.

Use open-ended questions to encourage group participation in the discussion. Focus the discussion on the feelings, thoughts and actions of the characters and on the purposes and consequences of their actions. Help participants relate their experiences to situations that they might have or will encounter. After the participants have completed the role play, commend everyone for their efforts. Discuss what you thought was good about the role play and then suggest areas for improvement. Make sure that each participant has an opportunity to participate in a role-play situation.

Two additional teaching strategies that may be used throughout the curriculum include the following:

4. *Universal Design for Learning strategies* provide a framework for teaching that accommodates people with more significant disabilities and/or unique learning styles. If your health promotion program has both health education and structured exercise classes for participants, you may find it useful to combine the curriculum lessons that have field trips with your structured exercise classes depending on group dynamics among the participants and group structure (e.g., time constraints, staff participant

ratio). The field trips are designed to integrate both the health education and exercise classes into an activity that will give participants opportunities to experience being physically active and making health food choices in their community. Lessons can be taught with or without the field trip activities.

Newsletters and cameras (digital and videos) can be used in every class as a way of including participants and having active involvement. Weekly newsletters can be used to summarize weekly class activities for participants and to encourage involvement of support persons by having participants share their newsletters. The newsletters are designed in three sections that include the following items: 1) health, exercise, and nutrition related information; 2) new types of exercises; and 3) summary of class discussions.

Through a joint project with Easter Seals, creative teaching strategies and solutions were developed for use with people who have severe/profound intellectual disabilities and a variety of physical disabilities. These strategies can be found in Appendix D.

5. Lifelong Learning Lessons (Appendix A) were developed based on our teaching experiences with participants in the community-based UIC Health Promotion Program for Adults with Developmental Disabilities. Based on participants interest in ongoing health education, 22 lessons were created as a way of initiating and encouraging lifelong learning related to health and adoption of healthy lifestyles. These lessons are designed to compliment the 36 lessons that are taught in the program to sustain long-term adoption of healthy lifestyles. Specifically, the aim of the classes is to reinforce the information presented during the “core” program and to provide ongoing support for people to continue developing new skills and greater confidence to engage in regular physical activity and make healthy food choices.

Classes in the Lifelong Learning Series can be taught based on individual needs and interest, and the topics have been arranged based on the core themes used in the lessons for the 12-week program. These themes are divided into four primary topics: 1) advocacy and social support, 2) exercise and physical activity, 3) nutrition, and 4) general health. Six of the nutrition lessons were developed through a project funded by Special Olympics International (SOI). Through the SOI project, these lessons were developed as a part of the *Learning Through Pictures: Nutrition and Physical Activity Education Curriculum for Adults with I/DD* (Sisarak & Marks, 2005).

Evaluation of Changes in Participants

Health Matters was designed to foster responsible, positive attitudes toward healthy behaviors for people with developmental disabilities. While these are long-term goals that may be difficult to assess, we can evaluate growth toward the goals. The purpose of the evaluation is to measure growth in participant knowledge, skills, and attitudes toward exercise and nutrition behaviors as well as improved social-emotional well-being. We recommend doing an evaluation at the beginning and at the end of the program.

The assessment tools that we use for the project were pilot tested and adapted for people with mild to moderate intellectual disabilities and were tested for their reliability and validity. These tools may not be appropriate for people with more severe intellectual disabilities. The evaluation tools are available in Appendix E.

Lastly, wherever possible, peer and self-evaluation should be encouraged. Help participants learn to evaluate themselves. Peer evaluation is an important part of the curriculum. If possible, solicit information from support persons to assist in the evaluation of participant progress with the objectives.