

Health and Health Promotion for Adults Aging with Intellectual and Developmental Disabilities

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Historical Perspective

- Specialized aging corner of segregated centers
- Senior services as “age appropriate”
- Person-Centered Planning for later life
- Being part of community
- Human rights (United Nations, 2006)
- Medicaid Home and Community-Based Services Final Rule (2014)

What is Successful Aging?

- **Aging without a disability?**
 - Ableism
- **Staying youthful?**
 - Ageism
- **“Compulsory youthfulness”** (Gibbons, 2016)
 - Intersectionality with disability studies
 - Old disabled as “failures”, diminished worth
 - Depends on ones choice and effort (Rowe & Kahn, 1998)
 - What is the state’s responsibility?

How Do We Address It?

- Explore how people with ID view aging
- Adopt empowered frameworks
 - Disability identity
 - Interdependence versus independence
- Take into account role of minority status, poverty, culture
- Take a life course approach

Aging Well

- Living on your own terms
- Adding value to society, family or friends
- Maintaining health and function



Extended Life Expectancy

- **Life expectancy similar unless they have**
 - severe levels of cognitive impairment
 - Down syndrome
 - cerebral palsy
 - multiple disabilities

What Does Growing Older Mean?

- *It means that you are settled and know what you are doing. I am more kinder, I get along a lot better. I have friends I am happy with and that I do things with.*
- *For the future I wish that I keep going happy and that I don't feel old and that I am not in a wheelchair.*



What Does Growing Older Mean?

- *I feel people 50 years and older have the same chances as younger people have – and more! Especially people with disabilities. Finally, I feel older people with disabilities shouldn't let their age or disability stop them from getting the job of their dreams or having fun.*



Interaction of Aging and IDD in Life Transitions

Development of chronic health conditions

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graph TD; A[Development of chronic health conditions] --> B[Changes in family caregiving and supports]; B --> C[Retiring from employment]; C --> D[Receiving end of life care];
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Changes in family caregiving and supports

Retiring from employment

Receiving end of life care

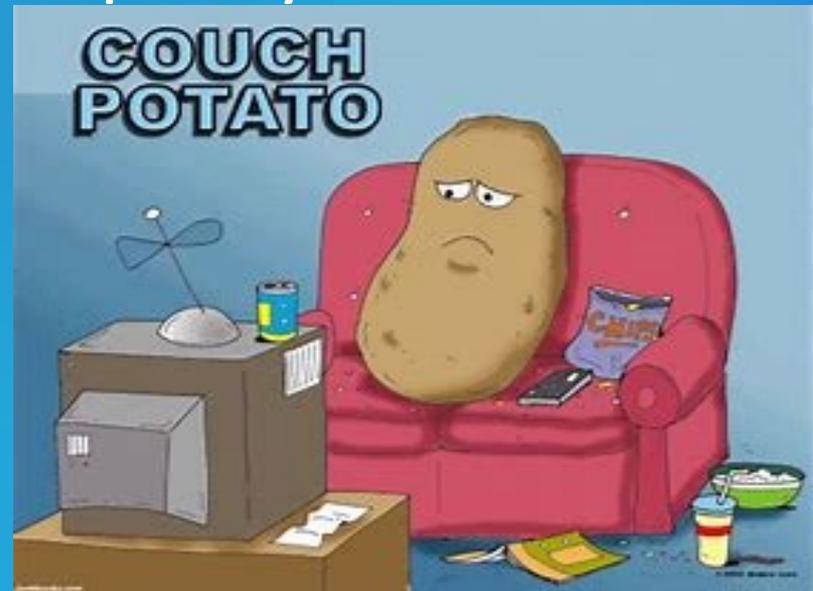
Health of People with IDD

- **Poorer health and earlier age related conditions**
 - Dementia
 - Osteoporosis
 - Oral health
 - Diabetes

- **Higher rate of falls**

Poorer Health Behaviors

- More obesity
- Sedentary behavior
- Unhealthy diets
- Related to health related quality of life



Access to Health Care

- Diagnosis of cancer at a later stage
- Polypharmacy
- Deaths amenable to health care intervention
- Lack of testing/treatment for COVID 19
 - Difficulty communicating symptoms
 - Understanding prevention instructions
 - Rationing
 - Prevention of support person at hospitals
 - Need to know the rights to equal access and support

Greater Susceptibility to COVID19

- Worse outcomes with age over 65
- Worse outcomes for those with chronic conditions
 - Heart, lung, diabetes, obesity
- More cases in long-term care settings
 - Twice as likely to die if get COVID
- Lack of understanding of safety precautions

Strategies to Reduce Disparities

Greater knowledge about impairment and treatments



Reduction in poverty and unhealthy environments



Improved health behaviors through health literacy and health promotion



Improved access, accessibility, equity, and effectiveness of health care



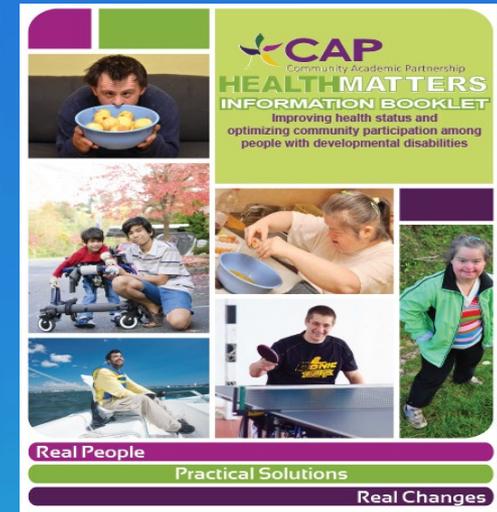
Better health and fitness in later life

Examples of Interventions in IDD and Health

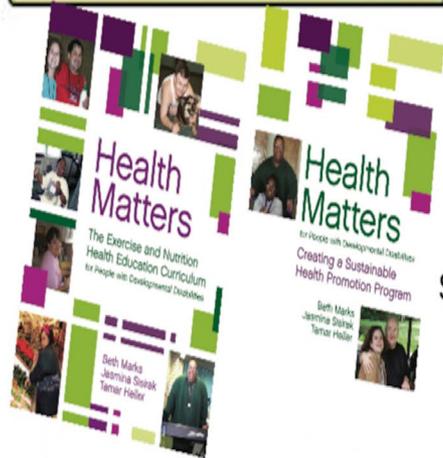
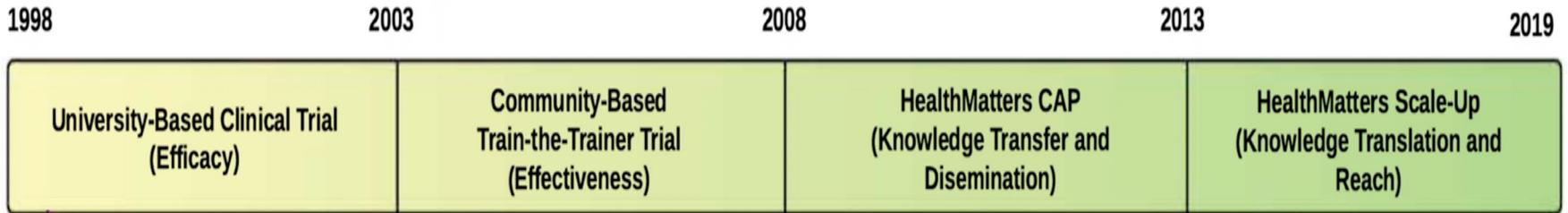
- **Health Matters: Exercise, Nutrition and Health Education Curriculum for People with DD** (Heller et al., 2004; Marks, Sisirak, & Heller, 2010)
- **Living Well with a Disability** (RTC: Rural, University of Montana)
- **We Walk** (Hsieh, 2019)

Other HealthMatters™ Programs

- Health Messages: Peer training
- Getting the Memo: Creating a culture of health promotion
- Signs and Symptoms: Observe changes in health conditions



Health Matters Program



Ongoing Dissemination of HealthMatters Train the Trainer: Certified Instructor Workshop
 >10,000 individuals with IDD served, >2600 Certified Instructors, 210 organizations, 35 states

Illinois
State-Wide Training

New Mexico
State-Wide Training

Organizational HealthMatters
Assessments

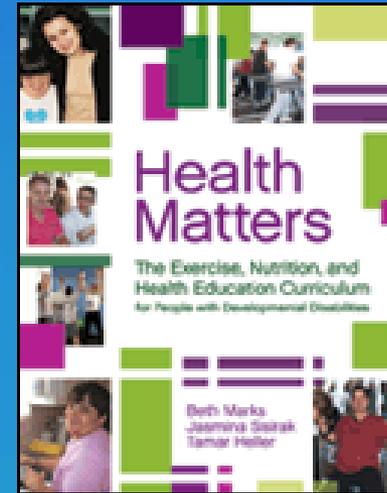
[HealthMatters Program.org](http://HealthMattersProgram.org)

Statewide Affiliates and Conferences

State-Wide Training
 Alaska
 Illinois
 Kentucky
 Maryland
 Missouri
 Nebraska
 North Carolina

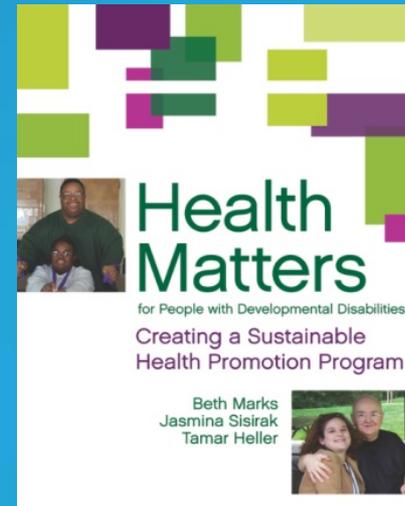
HealthMatters™ Program Intervention

- Exercise, Nutrition and Health Education Curriculum



Marks B, Sisirak J, Heller T. Health Matters: The exercise, nutrition and health education curriculum for people with developmental disabilities. Baltimore: Brookes, 2010.

- Train -the-Trainer Creating a Sustainable Health Promotion Program



Marks B, Sisirak J, Heller T. Health Matters: Health Matters for People with Developmental Disabilities: Creating a Sustainable Health Promotion Programs. Baltimore: Brookes, 2010.

Becoming Physically Active and Choosing Healthy Foods

Stages of Behavior Change

"I'm not interested"



Pre-Contemplation

"I'm thinking about it"



Contemplation

I'm Stopping!



Relapse

"I'm still doing it"



Maintenance

"I'm making plans"

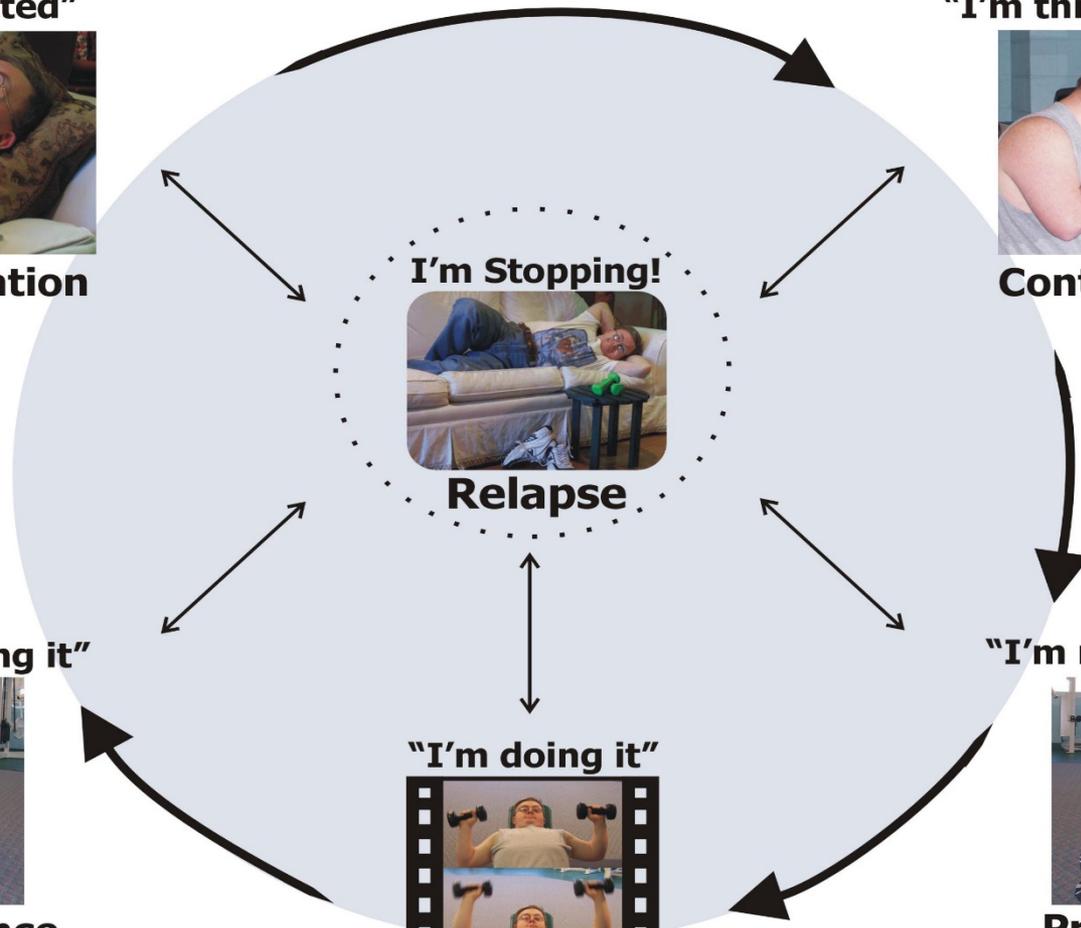


Preparation

"I'm doing it"



Action

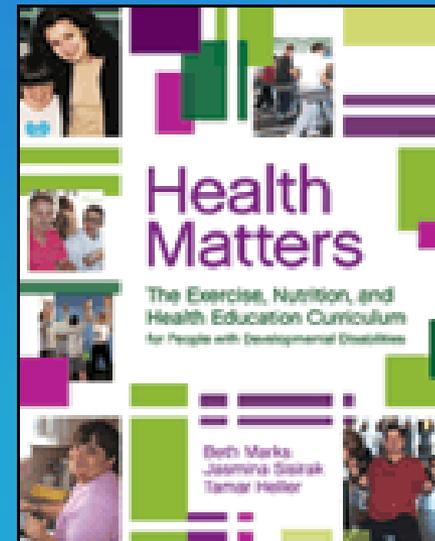


Fitness Classes



Health Education Classes

- 1 hour of health education class three days a week
- 36 interactive classes
- Personal notebook/tape
- <https://www.youtube.com/watch?v=Dyuk09cUCYo>



Exercise and Nutrition Health Education Curriculum Aims

- understand attitudes toward health, exercise and food
- find exercises that they like to do and set goals
- gain skills/ knowledge about exercising and eating well
- support each other during the course of the class
- identify places in their community to exercise



Curriculum Emphasizes

- self-determination and choice versus social control
- responsibility
- individual involvement in planning and meeting exercise goals
- changes in health behaviors in five stages
- support from caregivers

Good Pain

Bad Pain

PARTICIPANT HANDOUT: WHAT IS GOOD PAIN AND WHAT IS BAD PAIN?

What are different types of pain that you've had? Circle each answer.



Toothache



Back Pain



Falling Down



Fever/Flu/Cold



Sprain



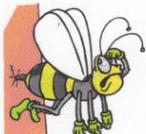
Broken Bone



Cut



Headache



Bee Sting



Stiff Shoulder



Burn



Stomachache

Good Pain

Mild burn when you exercise

Little soreness

Goes away fast

Bad Pain

Lasts for a long time

Constant or doesn't go away

Affects your walking

You cannot sleep

Unit 4

Lesson 25

What Is Good Pain and Bad Pain?

Health Matters: The Exercise and Nutrition Health Education Curriculum for People with Developmental Disabilities

Program : Baseline

- Over 2/3 reported receiving little support for exercising
- Over 50% lacked confidence to exercise
- Little knowledge and motivation
- Low strength and energy

Program Outcomes

(Heller, Hsieh, Rimmer 2004; Rimmer, Heller, Wang, Valerio, 2004)

↑↑ knowledge about exercise

↑↑ confidence in ability
to exercise

↑↑ life satisfaction

↑↑ physical activity, strength &
energy, Peak VO₂, & stair
climbing

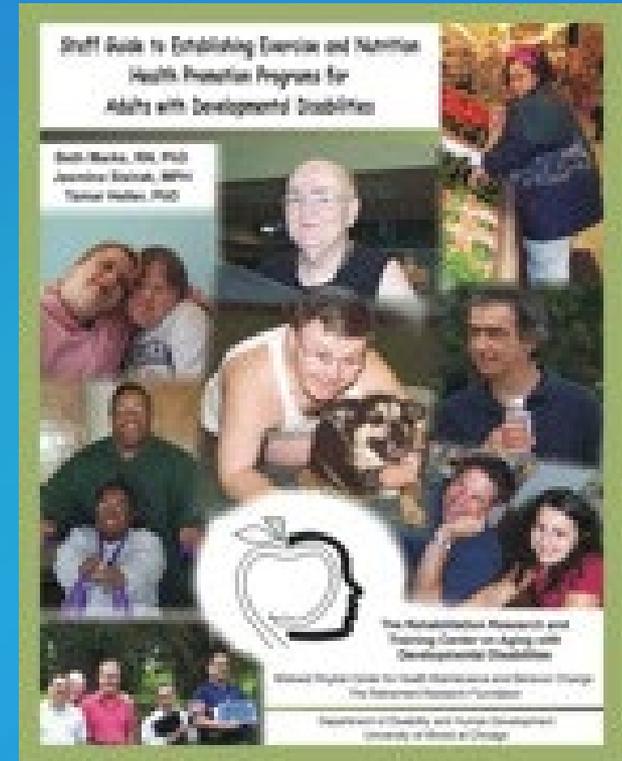
↑↑ caregiver perception
of exercise benefits

↓↓ Access barriers

Exercise and Nutrition Health Education for Adults with DD: Train-the-Trainer Curriculum

Provide staff with the skills, knowledge, and abilities to...

- Implement a physical activity (PA) and health education program
- Teach ways to increase PA and healthy food
- Support to maintain long-term lifestyle changes.



Staff Health and Attitudes

- 63.7% overweight or obese (BMI over 25)
- 32% smoking
- If perceived fewer exercise barriers, more health promoting behaviors
- More health promoting behaviors related to better health status

Impact of Training on Staff

(Marks, Sisirak, & Chang, 2013; Pett, et al., 2013)

- Improved energy and less pain
- Improved psychological well-being
- Positive exercise/nutrition expectations
- Environmental supports for nutrition
- Knowledge of fruit and vegetable intake recommendations
- Organizational policies that support health promotion for direct care workers

Impact on Adults with I/DD

- Adults age 30 and over (n=52)
- Participated in 12 week , 3 days per week exercise and health education program
- Compared to controls showed:
 - Less pain
 - Increased self-efficacy
 - Increased social environmental support

Exercise Classes

- 1 hour of physical activity 3 days/week
- Emphasis on flexibility, cardiovascular endurance, muscle strength, balance
- Follow guidelines for frequency, intensity, stretching
- Use the equipment and exercise safely

Tips for Starting a Program

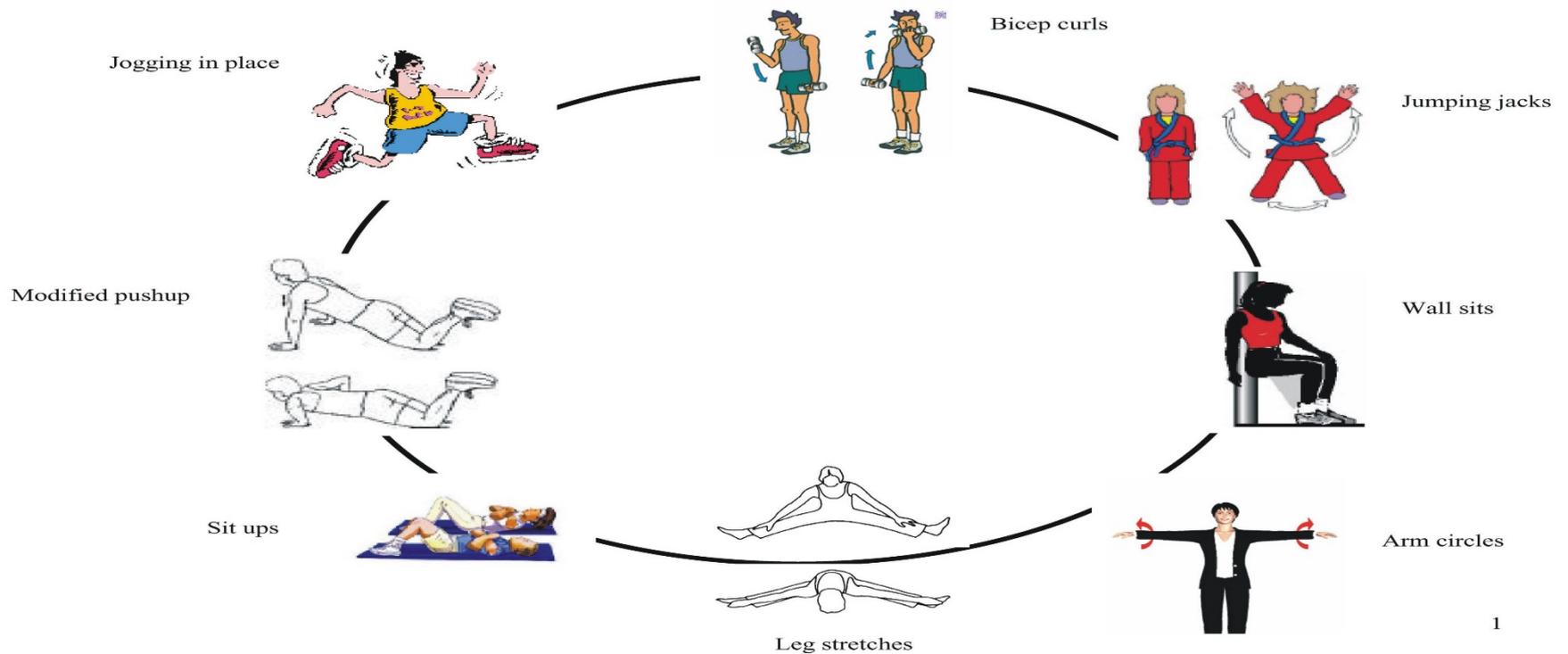
- Get an OK from a health care provider
- Incorporate PA throughout day
- Tailor made for person
- Exercise a minimum of 3 days/30 minutes (moderate intensity)
- More benefits if more rigorous (moderate to vigorous for 60 minutes)
- Make it progressive
- Keep it fun and rewarding
- Foster fitness among staff and caregivers

Program Plan Inventory

- How many participants/clients in the program?
- What is the number of staff available ?
- How much time?
- How many sessions per week?
- What is the size of the space?
- What kind of assistance do our clients use?
- What resources and equipment do we have available?
- Do we have staff that are doing and/or are interested in specific physical activity?

Sample Programs: No Equipment

Sample Circuit Training



Caregiver Support for Exercise

Staff/family members can support:

- Give encouragement to stick with it
- Offer to exercise together
- Plan for exercise on recreational outings
- Discuss ways to get more exercise
- Ensure transportation
- Identify ways of paying
- Show how to exercise



Caregiver Support for Nutrition

Staff/family can influence choice/control in meal preparation and access to food
Support can be provided:

- Encourage healthy food choices
- Assist in developing plans and goals for changing eating habits
- Remind people to avoid high fat, salty foods and to eat more fruits and vegetables
- Compliment people on changing eating habits
- Offer fruits and vegetables as a snack



Sustainable Health Promotion Programs

- Supportive environment and attitudes within your organization
- Policies supporting health and safety
- Supportive attitudes among staff and management for healthy lifestyles for adults with I/DD and themselves



Spreading the Word

- Work with a local /state entity
- Conduct Request for Proposals
- Conduct webinar trainings with certified instructors
- Develop wellness committees
- Conduct HM Assessments and evaluation
- Implement program
- Develop sustainability plan

HealthMatters, Kentucky!

CBO Interest and Commitment

1. HealthMatters Assessments

- 146 Service providers in Kentucky in 2014

2. Getting the Memo Webinar

- 270 Service providers participated

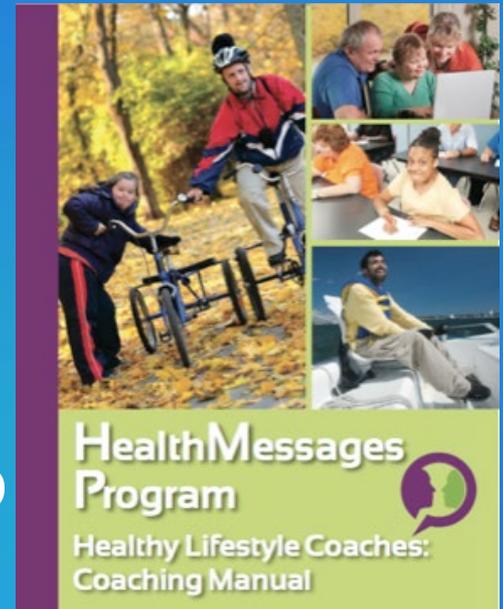
3. *HealthMatters, Kentucky:* Scale-Up Research Project

- CBOs completing letter of commitment
- *HealthMatters Webinar Workshops* to teach staff to start a *HealthMatters Program*

Peer to Peer Health Messages

Phase 1 (Marks et al., 2019)

- Train-the-trainers program to teach adults with IDD to become coaches along with staff mentors
- Focused on teaching participants to increase their weekly PA and to drink more water
- 75 minute webinar, toolkit/coaching manual
- Paired with mentor in learning content and developing leadership skills



Phase 2 Peer-Peer Messages

- Deliver 12 sessions with about 10 people
- Booklets and 2 wristbands displaying the weekly health messages
 - One to keep
 - One to pass on the message to another

Why Peer Coaches?

- Can share health messages
- People are about the same age
- Common interests
- Benefits the coaches as well

Outcomes of Peer to Peer

- 34 staff and 67 adults with IDD aged 30 plus
- Randomized intervention results:
- Coaches increased PA and hydration knowledge
- Mentors increased confidence to teach program
- Program participants
 - increased PA and hydration knowledge
 - increased social support for engaging in PA
 - Improved PA and hydration
- Need to include health promotion in CBO mission, vision and job descriptions

We Walk Program (Hsieh, 2019)

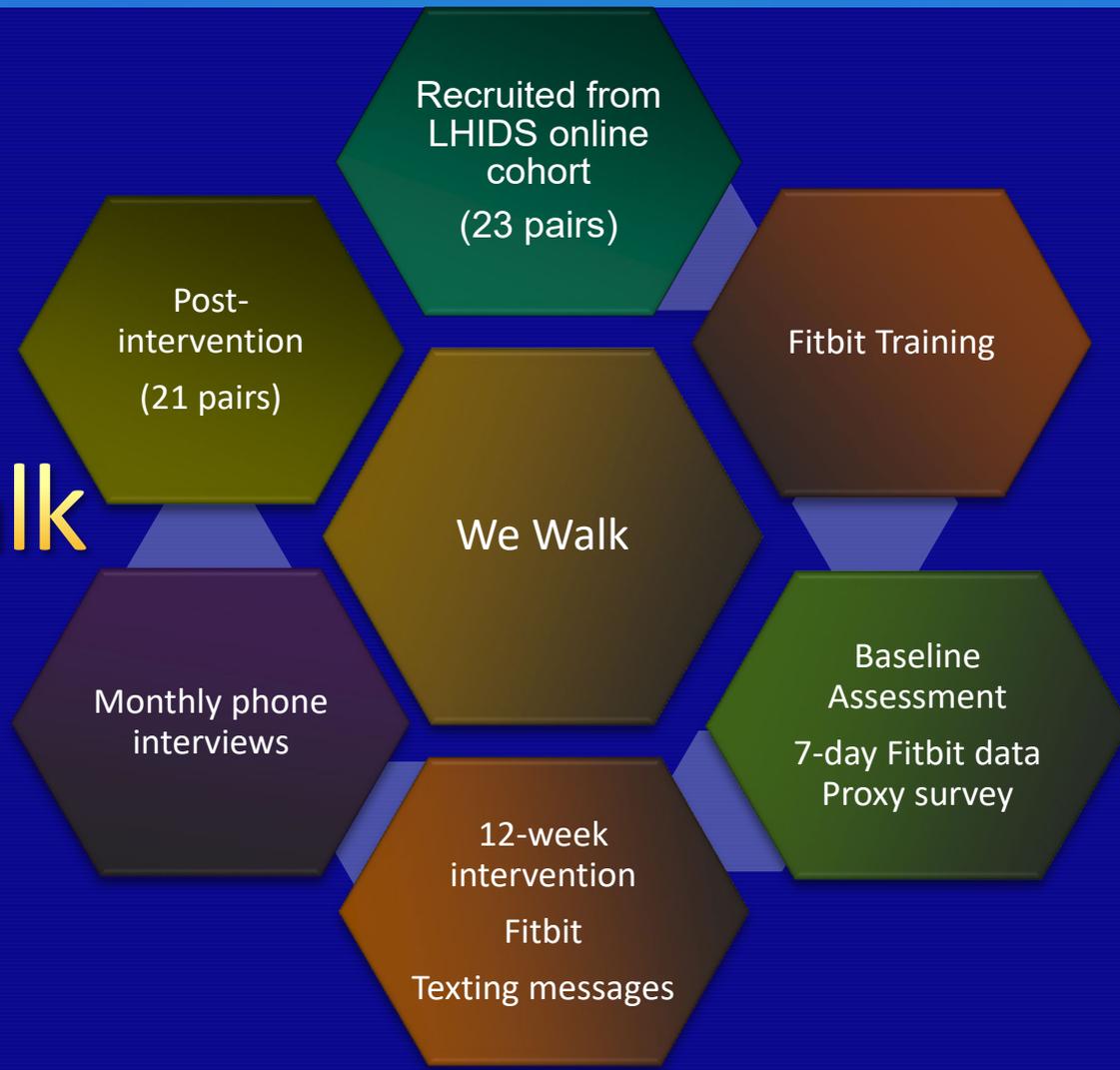


- “We Walk,” a technology intervention to improve the PA of adults with ID and their family caregivers.
- Use of technology intervention in promoting PA in adults with ID and their family caregivers

Study Design and Results

- A single group pre-post design
- Driven by social cognitive and self-efficacy theories (Bandura, 1986; Bandura, 1997)
- A 12-week walking program with wearable PA trackers(i.e., Fitbit Charge HR) and texting messages intervention
- Increase in moderate and vigorous physical activity

We Walk



Key Issues in Health Care

- **Rationing of health care for older and disabled?**
 - Organ transplants
 - Dialysis
- **Key criteria**
 - Years of life expectancy
 - Ability to keep regimen
 - Amount of support available
- **Will these interventions improve quality of life balanced with burden for person and carers?**

Key Issues in Health Care

- **Health checks and preventive screening**
 - Risk versus benefits
 - Equality of access
- **Patient centered care and health literacy**
 - Need for health literacy education
 - Time for listening
 - Carer involvement
- **Generic versus specialized services**
 - Case of woman in generic nursing home

What is Good Healthcare?

- **Getting needs met through access to quality services.**
 - *“I was able to receive a good psychiatrist, one that has been really helpful to me, and I was able to get my glasses.”*
- **Humanizing treatment by healthcare professionals**
 - *“The doctors have been listening and they find the better solution.”*

What is Good Healthcare?

- **Skilled, knowledgeable, and experienced providers**
 - *“My doctors tells me to take my pills every day and sees how I am doing.”*
- **Accessible communication**
 - *“My doctors take care of me good, I understand when they talk to me.”*

What are Barriers to Good Healthcare?

● Doctors who did not demonstrate respect for them

- *“I am unhappy with my doctor...if he’s the only one there, I won’t go...I know that’s bad for my health but...he is very rude and makes me feel stupid...I know my body and I know if something is wrong with me...he thinks he’s better and smarter than I am and we bump heads.”*

● Delays in getting services

- *“I needed a personal assistant and it took a long time, had to have family members help and they didn’t always know what to do.”*

Disparities in Health Care Quality

- **Lower healthcare appraisal**
 - Having worse health status
 - Living in institutional settings
 - Having more unmet transportation needs
- **More unmet healthcare needs**
 - Having worse health status
 - Being a racial/ethnic minority
 - Also having a physical disability

Other Factors in Healthcare Quality

- **Greater family involvement**
 - input in healthcare decisions
 - family support needs met
- **Better care coordination**
 - knowledgeable care coordinators
 - respectful of ones wishes and input

Journey to Better Healthcare

- My Health Passport:
- Important in pandemic
- <http://bit.ly/VJ3rtG>



The image shows a 'My Health Passport' form. At the top, there are two blue squares with a white 'H' on a red background, flanking the title 'My Health Passport'. Below this is a yellow banner with a red exclamation mark on each side, containing the text: 'If you are a ~~health care professional~~ who will be helping me, PLEASE READ THIS Before you try to help me with my care or treatment.' The main form area has a red border and contains several fields: 'My full name is: _____', 'I like to be called: _____', 'Date of birth: / / _____', 'My primary care physician: _____', and 'Physician's phone number: _____'. To the right of these fields is a box with a grey silhouette of a person and the text 'Attach your picture here!'. Below the fields, there is a paragraph: 'This passport has important information so you can better support me when I visit/stay in your hospital or clinic. Please keep this with my other notes, and where it may be easily referenced'. Below this paragraph are two lines for 'My signature: _____' and 'Date completed: / / _____'. Further down, there are two lines for 'You can talk to this person about my health: _____' and 'Phone number: _____ Relationship: _____'. At the bottom, there is a red-bordered box with a blue speech bubble icon containing a person and the text: 'I communicate using: (e.g. speech, preferred language, sign language, communication devices or aids, non-verbal sounds, etc. state if extra time support is needed)'. Below this text are three horizontal lines for additional information.

End of Life Issues

- Under-recognition of health issues
- Need for palliative care training
- Greater barriers to hospice care
- Understanding of death and losses (disenfranchised grief)
- Training needs of staff

Death and Dying Curriculum

- **Teaching concepts of death**
 - Causes
 - End of life functions
 - All die
 - Can't return to life
- **Understanding grief**
 - Emotional responses
 - Behaviors

Death and Dying

- **Mourning**

- Death happened
- Feel pain
- Get used to losses
- Begin to do new things

- **Turning to others for comfort**

- **Rituals (account for religion and culture)**

- Funerals
- Visitation

Assisted Suicide and Disability

- **Allowed in 5 U.S. states**
 - 51% U.S. pro-assisted suicide
- **Equating disability with poor “quality of life”**
- **Concern about “burden” on family**
- **Terry Schiavo case**
 - not terminal
 - withdrawal of food and water



Need for Bridging Aging and Disability

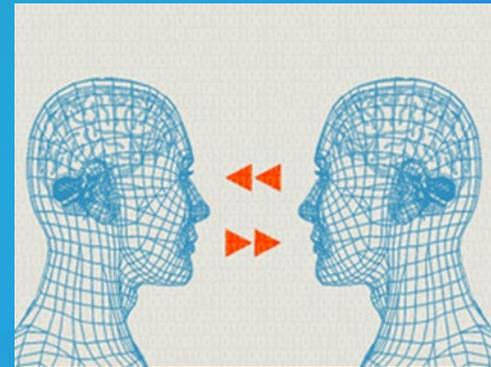
- **AGING** as a field has a lot to contribute to the **DISABILITY** and vice versa
- **Many common needs**
- **Efficiency in services**

Challenges in Bridging Aging and Disability

- Historical segmentation of service systems
- Different philosophies, terms, and definitions
- Distinct fields of knowledge and practice, limited sharing or exchange
- Protection and duplication of funds
- Missed opportunities for knowledge translation, innovative policy change, and co-funding

How Do We Bridge Aging and IDD?

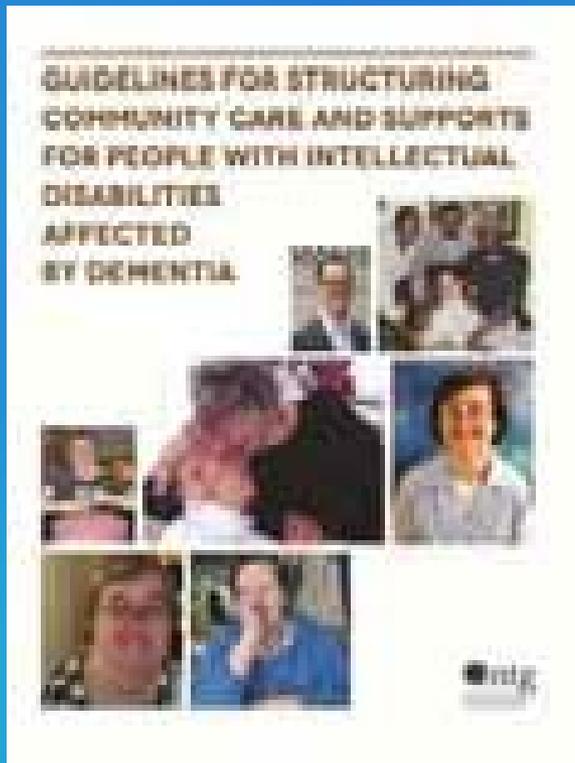
- Exchange of research
- Adaptation of interventions
- Development of policy embracing ideas from both fields



Adaptations from Aging

- **Geriatric Assessments (Hahn)**
- **Falls Prevention Programs (Otago Program)**
- **Chronic Disease Self-Management**
 - Diabetes adaptations for DD (Centers for Excellence in Aging and Community Wellness, University of Albany)

Inclusion in National Initiatives



- National Plan to Address Alzheimer's Disease (NAPA)
- National Task Group on ID and Dementia Practices (NTG)
 - www.aadmd.org/NTG
 - NTG projects funded (ACL)
 - FL, ME, RI, HI

National Task Group on ID and Dementia Practices

- 3 day workshops on dementia in 17 states with 1300 support workers with 500 staff using curriculum
- Co-sponsor 1018 NDSS Adult Down Syndrome Summit for family caregivers of older adults with DS
- On-line support group for families
- NTG caregiver newsletter
- Caregiver's guide for families in Rhode Island

Building From the Best of the Disability and Aging Systems

- **Planful cooperation** can help institute proactive and helpful screenings, interventions, and programmatic supports, and cooperative cross-cutting research
- **Models** to cooperatively deliver services and increase the public benefit
- Given growth of the aging population, 'special' populations call for **special attention and collaborative planning**

Looking to the Future

- Greater use of technology and universal design to address age related changes
- Use of dissemination through web based training
- Pressure on system and families with lack of work force and community capacity
- Growing recognition of supportive decision-making and interdependence
- Need for research on better ways to bridge aging and IDD

Contact Us

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**DISABILITY AND
HUMAN
DEVELOPMENT
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APPLIED HEALTH
SCIENCES**

