

# Challenges and Opportunities in Serving Adults Aging with Intellectual and Developmental Disabilities

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OASIS Community

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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?

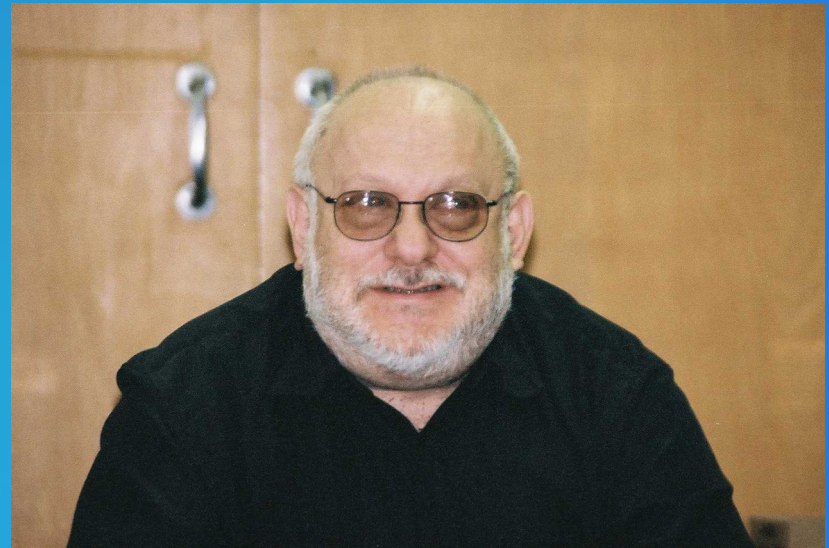
- **Aging without a disability?**
  - Ableism
- **Staying youthful?**
  - Ageism
- **“Compulsory youthfulness”** (Gibbons, 2016)
  - Intersectionality with disability studies
  - Old disabled as “failures”, diminished worth
  - Depends on ones choice and effort (Rowe & Kahn, 1998)
  - What is the state’s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

Changes in family caregiving and supports

Retiring from employment

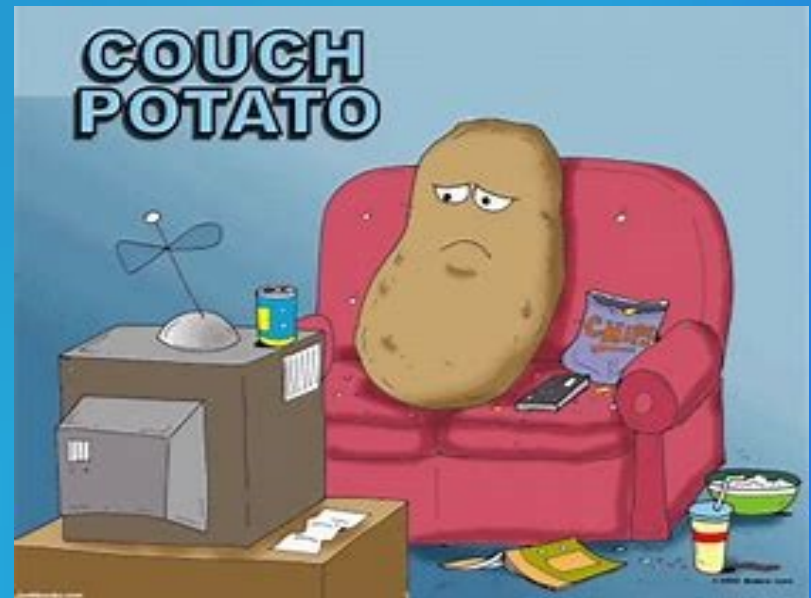
Receiving end of life care

# 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

# 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

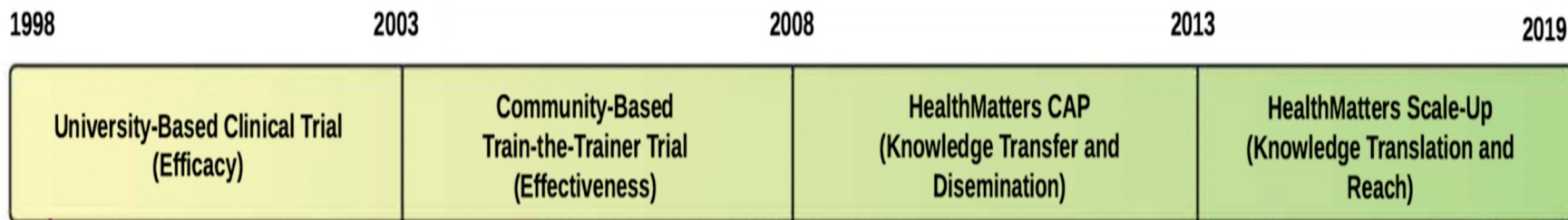


Better health and fitness in later life

# 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)

# 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

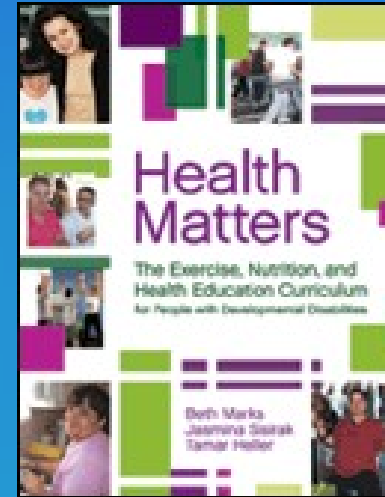
Statewide Affiliates and Conferences

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



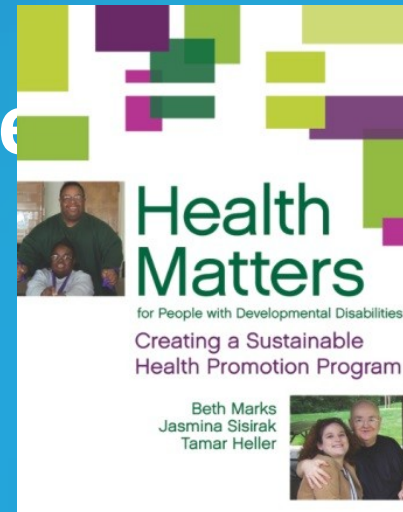
# HealthMatters™ Program Intervention

- 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
- Virtual Future is Now



*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"



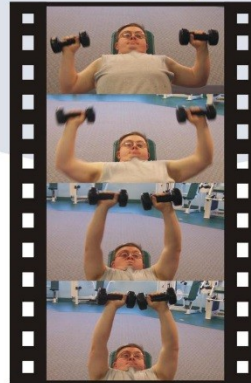
**Maintenance**

"I'm making plans"



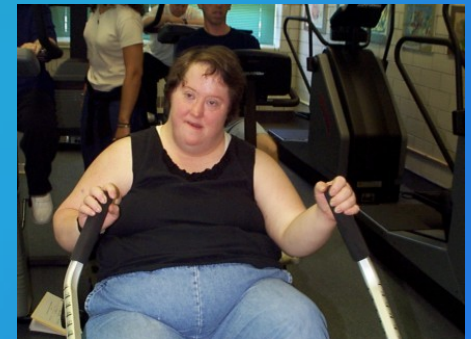
**Preparation**

"I'm doing it"



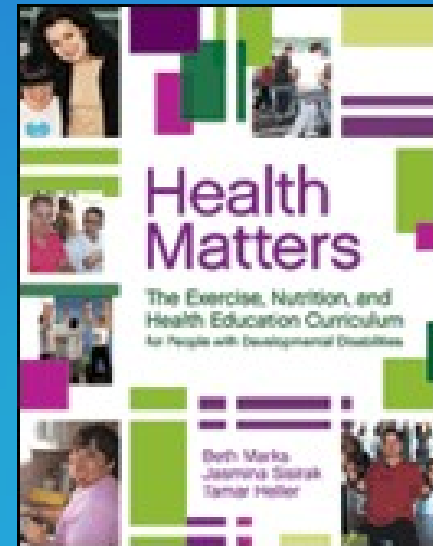
**Action**

# 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



# 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 VO<sub>2</sub>, & stair  
climbing**

↑↑ **caregiver perception  
of exercise benefits**

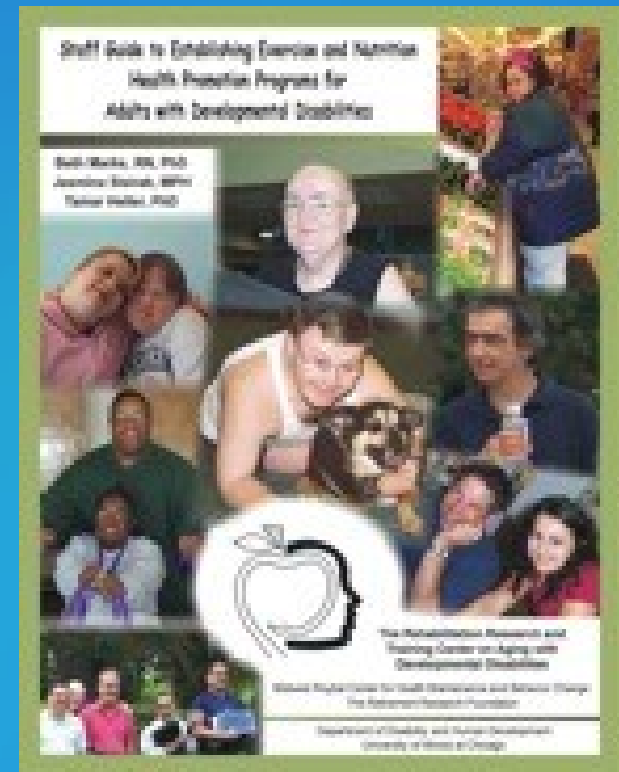
↓↓ **Access barriers**



# 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
- 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

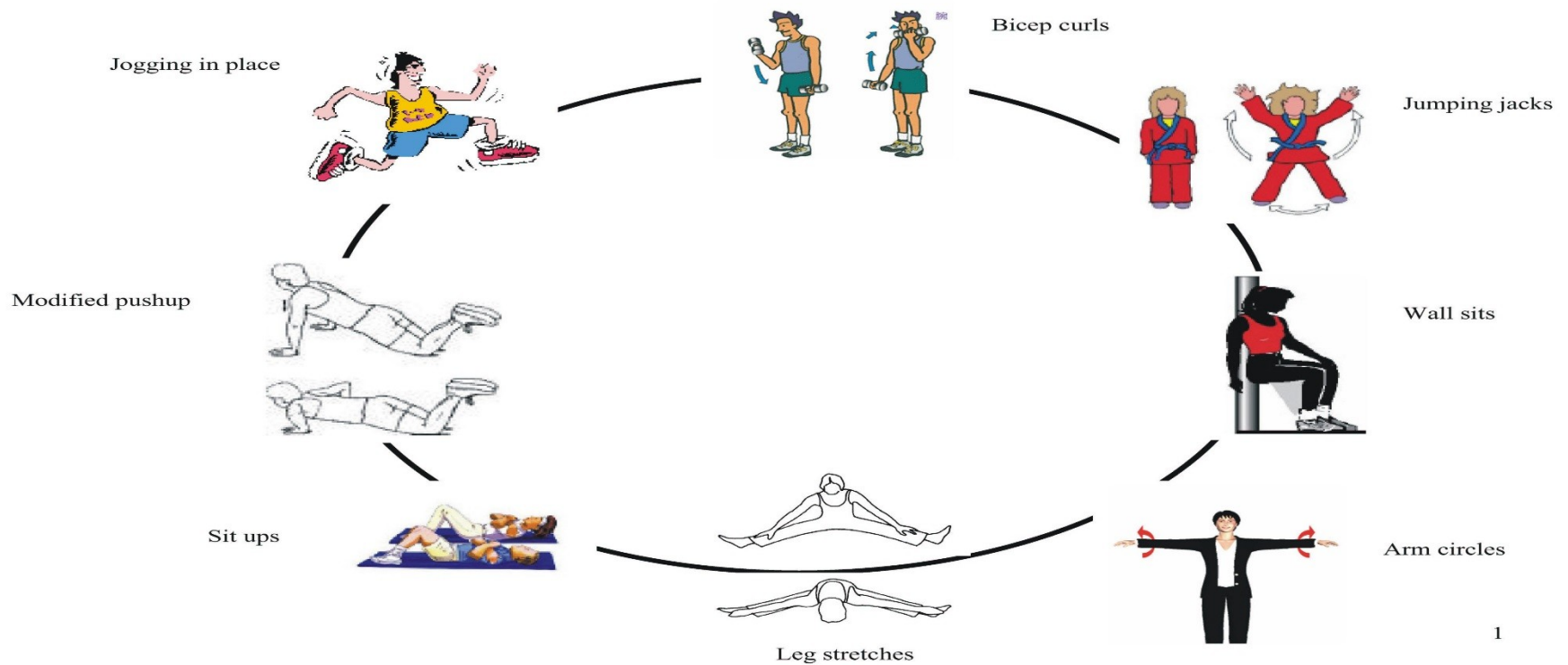
- Get an OK from a health care provider
- Incorporate PA throughout day
- Tailor made for person
- Exercise a minimum of 3 days/30 minutes (moderate intensity)
- More benefits if more rigorous (moderate to vigorous for 60 minutes)
- Make it progressive
- Keep it fun and rewarding
- Foster fitness among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



# Sustainable Health Promotion Programs

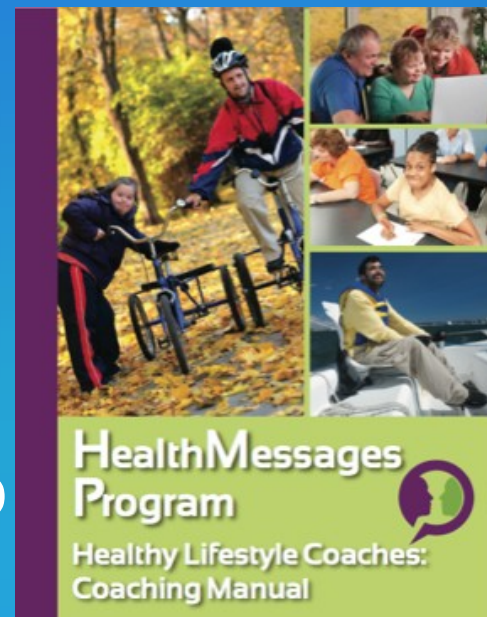
- Supportive environment and attitudes within your organization
- Policies supporting health and safety
- Supportive attitudes among staff and management for healthy lifestyles for adults with I/DD and themselves



# 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

- 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 agency 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
- 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

# 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 is a red banner with the text 'My Health Passport' and two blue squares containing a white 'H'. Below this is a yellow banner with a red exclamation mark icon and 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: \_\_\_\_\_' and 'Relationship: \_\_\_\_\_'. At the bottom, there is a box with a blue speech bubble icon 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 box are three horizontal lines for additional information.

# None of Us Want to Stand Still

- Documentary on health care and IDD
- Voice to advocates to share their stories
- Examples of how changes can be made on all levels of a healthcare organization to better treat these patients.
- Produced by Rush University Medical Center and Georgetown University Center for Excellence in Developmental Disabilities.
- <https://vimeo.com/415331167>

# Families and Long-Term Services and Supports (LTSS)

- More likely to live with parents
  - About 20% with aging (over age 60) parents in IN)
- Often need LTSS life-long (30,276 in IN)
- Families and persons with disabilities need to engage in future planning

# Life-Long Impact for Families

- Fewer opportunities for employment
- Restricted social network
- Impact on physical and mental health and stress for some groups
- Greater difficulties as parents and person with IDD age
- Caring also has its positive aspects

# Gaps in Family Support

Only 15% of families caring for person with IDD received public family support (Braddock et al., 2017)

# Worry about Future Care

## ● “I wish my child dies 4 minutes before I do”

### Four Bodies in Elmhurst

Why would an 82-year-old man kill his son, his daughter, his wife and himself?

Photo by Jeff Himmelman, Dec. 2, 2015 / New York Times



### Experts say probation understandable for woman who killed disabled daughter

Liltz pleaded guilty to involuntary manslaughter in the death of her daughter.

Photo by Stacey Wescott / Chicago Tribune  
Bonnie Liltz and her attorney.



# Siblings as the Club Sandwich Generation



# Family Ties: Siblings as Longest Lasting Relationship

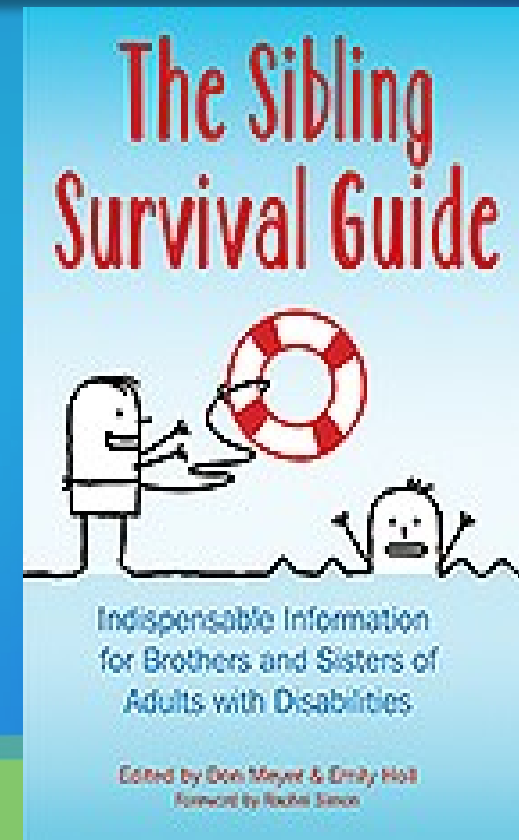




# Sibling Leadership Network

- Over 5500 siblings and supporters
- 27 state chapters
- Started in 2007
- Resources, research, advocacy

[www.siblingleadership.org](http://www.siblingleadership.org)



# National Community of Practice for Supporting Families

Charting the Life Course

([www.lifecourse.com](http://www.lifecourse.com))



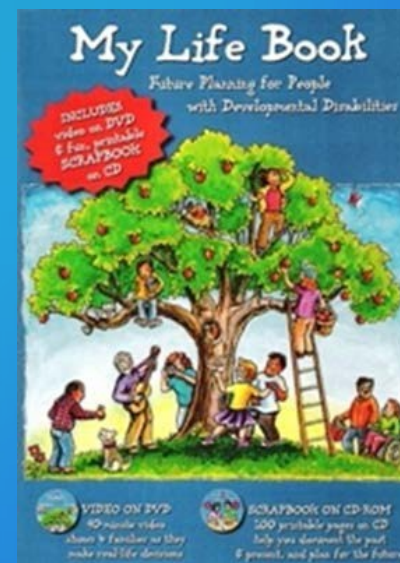
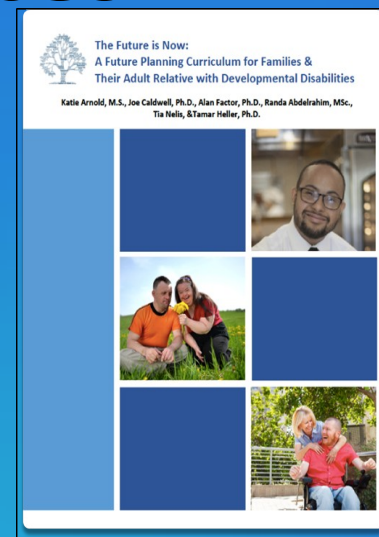
# Family Support Interventions

- **Family Support Research and Training Center Promising Practices**
  - Caring for the Caregiver
  - Future is Now



# Future Planning Resources

- *Future is Now* (Heller & Caldwell, 2006)
- *PLAN* (Etmanski) Canada
- Use of social media to support families (Hoosier TYZE Project)
- The Arc Center on Future Planning  
[www.futureplanning.thearc.org/](http://www.futureplanning.thearc.org/)



# Development and Purpose of The Future is Now



The Future is Now:  
A Future Planning Curriculum for Families &  
Their Adult Relative with Developmental Disabilities

Katie Arnold, M.S., Joe Caldwell, Ph.D., Alan Factor, Ph.D., Randa Abdelrahim, MSc.,  
Tia Nelis, & Tamar Heller, Ph.D.



- **Background:**
  - Research showing need & input from stakeholders
  - Experience with different interventions
- **Purpose:**
  - Develop future planning goals
  - Develop letter of intent
  - Increase advocacy for supports
- **Caregivers experience less burden, including less worry about future**
- **Persons with IDD have greater voice in decisions about their life**

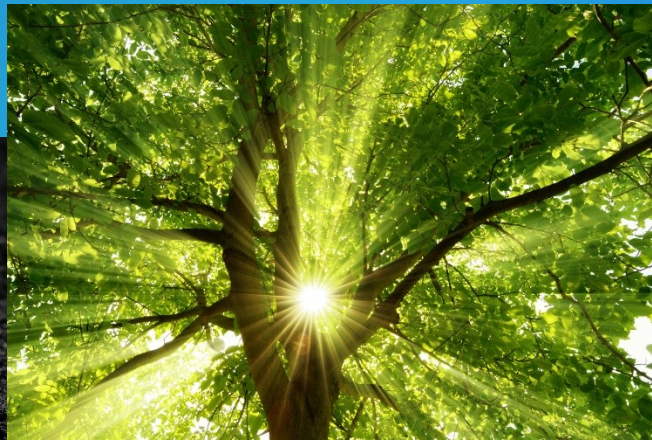
# Aspects of the Curriculum

- Taking the First Step : Identifying Dreams and Nightmares
- Building Relationships and Support Networks
- Desired Living Arrangements
- Post-Secondary Education, Work, and Retirement Opportunities
- Identifying Key Succession Person



# Structure of Training

- Learning takes place over time
- Families learn from each other and support each other to take risks.
- Homework assignments completed jointly by families and their relative with a disability
- Breaks the process down into manageable steps



# Overview of The Future is Now Curriculum

- Pre-session on legal/financial planning
- Facilitators guide for families
- Workbook for families
- Facilitators guide for people with disabilities
- Workbook for people with disabilities



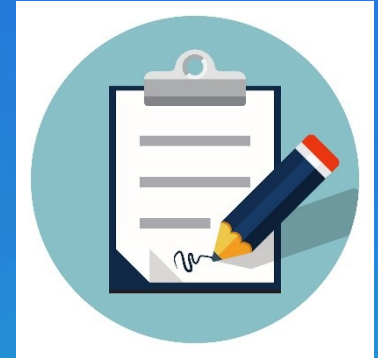


# Unique Features



- **Integration of person-centered and family-centered philosophies**
- **Peer support**
- **Inclusion of Peer Trainers**
- **Problem solving around family dynamics and family values**
- **Focus includes both current and potential community supports**

# Letter of Intent



- Includes essential information about the individual with a disability's strengths, preferences, interests, support needs, and health.
- Identifies goals:
  - to expand friendships and supports;
  - make future living arrangements;
  - arrange for postsecondary education, work, or retirement; and
  - designate a successor caregiver.

# 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

- **Contribute to each other** **other**  
**versa**
- **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



# 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)
- **Family Caregiving**
  - Family Support Research and Training Center (UIC)
  - Caring for the Caregiver (Kennedy Center and SE Connecticut Agency on Aging)
- **Aging in Place, Aging in Community, Disability and Aging Friendly Communities**

# Employment and Retirement

- 2020-2021 National Core Indicators data:
  - 23% in ID vs 15% US in integrated paid job
  - 44% in ID vs. 50% US would like job
  - 18% in ID vs. 17% in US do not want job since they are retired
- Mostly in facility based and non-work setting (Winsor et al., 2017) including retirement options, such as volunteering, recreational and health promotion activities, senior center participation, and continuing education (Sulweski et al., 2017).

# Transition to Retirement

- Attending community group or volunteering
- Use of Mentors
- Planning meeting
- Training of mentors
- Choice of activities and mentors
- Ongoing support



Stancliffe, Bigby, Balandin, Wilson (2013)

# Engaging with Aging: Person Centered Planning for Later Life (Heller et al. 1996; Heumen, Scott, & Heller, 2018)

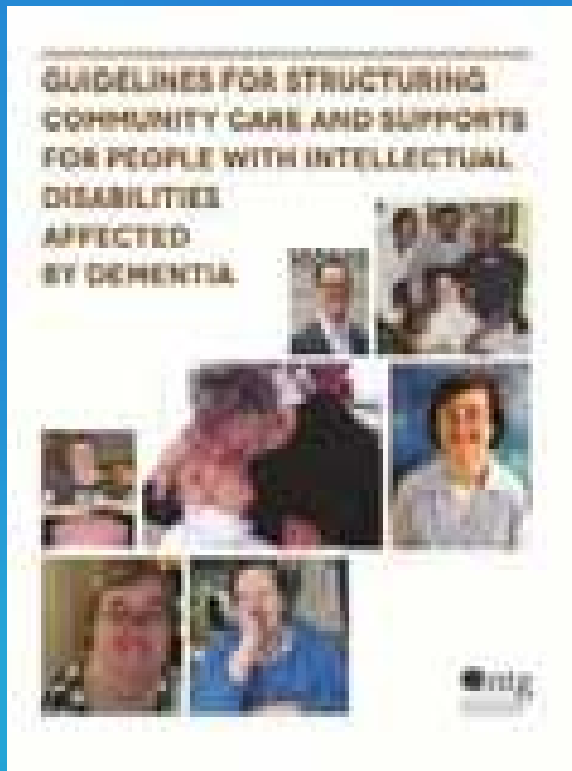
- Understanding Aging and Life Stages: Life Story
- Rights & Choice Making
- Exercise I and II
- Healthy Eating
- Stress Reduction
- Where We Live
- Friendships & Community Supports
- Work, Volunteering, & Free Time
- Review & Goal Setting



# Opportunities for Common Ground

- Administration for Community Living
  - Aging and Disability Resource Centers
  - National Respite Act
  - National Family Caregiving Support Program
  - National Alzheimer's Project Act
  - Chronic Disease Self Management

# 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](http://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** : screenings, interventions, and programmatic supports
- **Models** to cooperatively deliver services
- **Bridging Aging and Disabilities Networks to Support Future Planning of Adults with IDD and Their Families** (The National Association of Councils on Developmental Disabilities (NACDD))



# Looking to the Future

- Greater use of technology and universal design to address age related changes
- Transportation assistance
- 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

Funded by National Institute on Disability, Independent Living and Rehabilitation Research, Administration on Community Living, grant # 90IFRE0051 to the University of Illinois Chicago.

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