

# Aging in Place and Adults with Intellectual and Developmental Disabilities

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North Dakota Center for Persons with Disabilities:  
Collaboration for Change Webinar Series

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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)

# What is Successful Aging?

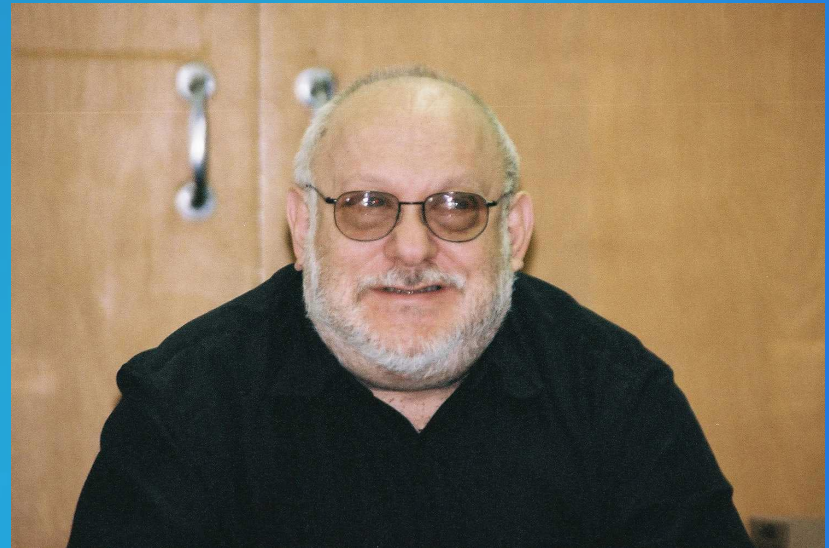
- **Aging without a disability?**
  - Ableism
- **Staying youthful?**
  - Ageism
- **“Compulsory youthfulness”** (Gibbons, 2016)
  - Intersectionality with disability studies
  - Old disabled as “failures”, diminished worth
  - Depends on ones choice and effort (Rowe & Kahn, 1998)
  - What is the state’s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

# Healthy Aging

- 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

# 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

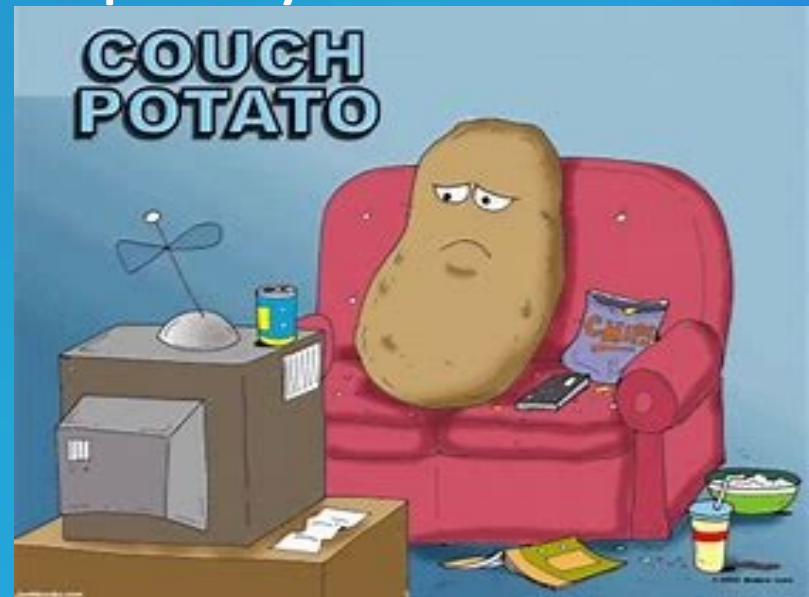
# Health of People with IDD

- **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

# 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

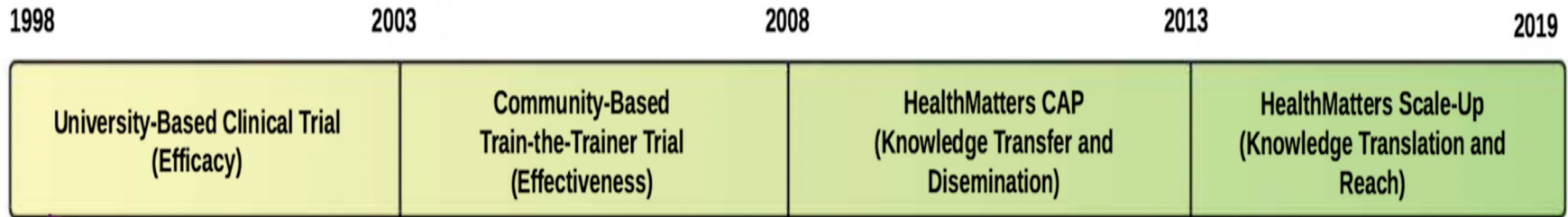


Better health and fitness in later life

# 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](http://HealthMattersProgram.org)

Statewide Affiliates and Conferences

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

# Health Education Classes

- 1 hour of health education class, 1 hour exercise 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





# 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!**



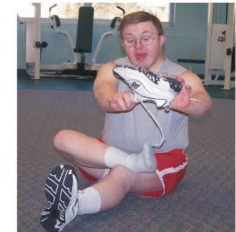
**Relapse**

"I'm still doing it"



**Maintenance**

"I'm making plans"

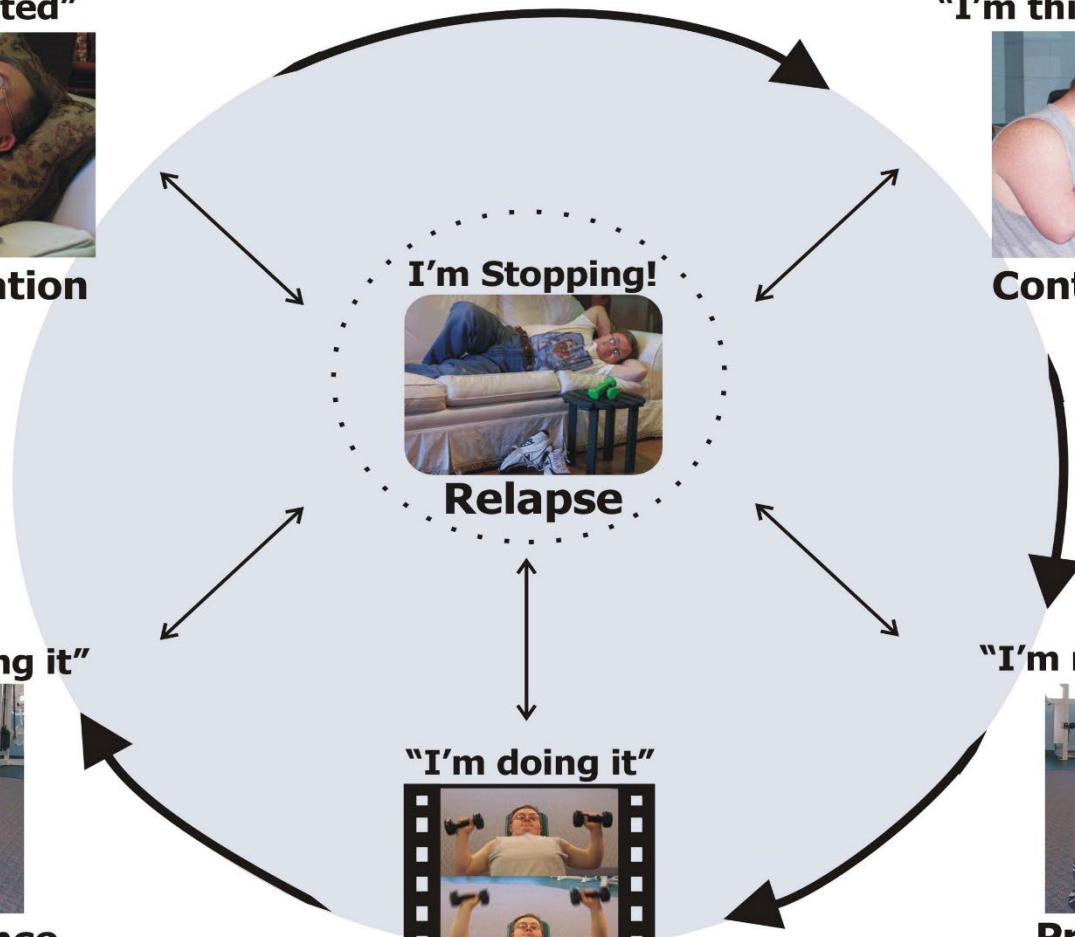


**Preparation**

"I'm doing it"



**Action**



# 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.



# Train-the-Trainer Curriculum

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

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

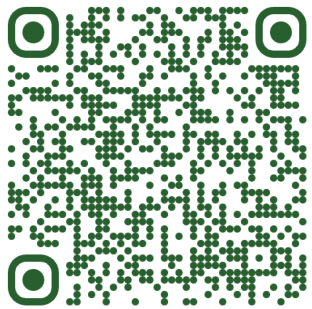
# Impact on Adults with IDD

- 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



## Health Promotion Programs with Evidence that Work

### Virtual Coach: HealthMatters



## VIRTUAL COACH

### HealthMatters Program\*

Research based, field tested health promotion program that provides service provider organizations strategies and materials to support healthy options and choices for people with intellectual and developmental disability (IDD).

\*Meets the Administration for Community Living OAA Title III-D Evidence-Based Requirements



#### 1 THE TRAINING

HealthMatters Program Train-the-Trainer Certified Instructor Workshop

- 6-hour online
- organize and start a tailored physical activity & health education program for people with IDD

#### 2 THE CURRICULUM

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

- adaptable instructor scripts for each lesson
- participant handouts & worksheets
- 59 lessons on health, exercise, nutrition, choice-making, self determination

#### 3 THE PROGRAM

12-Week HealthMatters Program for People with IDD

- group physical activity and health education
- 36 lessons, 3x per week, 4-6 hours weekly

#### 4 THE CLASSROOM

Virtual Coach

- multimodal supplement to the Curriculum
- 36 lessons, resources, infographics, videos
- virtual support allows for an interactive communication, feedback, resource sharing, and collaborative learning



# Virtual Coach Reach : Since Launched in 2020

- 8 Countries and 8 states participated in Program
- 10,000 participants with IDD received programming
- 147 community based organizations participated in Virtual Coach Train-the Trainer
- 2800 community based staff trained and certified

# We Walk Program (Hsieh, 2019)



- “We Walk,” a 12 week technology intervention to improve the PA of adults with ID and their family caregivers.
- Use of technology intervention (e.g., fitbit) and text messaging in promoting PA in adults with ID and their family caregivers
- Increase in moderate and vigorous PA



# 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

# Factors Associated with Disparities in Health Care Quality

- Having worse health status
- Living in institutional settings
- Having more unmet transportation needs
- Being a racial/ethnic minority
- Also having a physical disability
- Less family involvement
- Poorer care coordination

# 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 large white 'H' characters on blue backgrounds. 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: / / \_\_\_\_\_'. Below that 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 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.

# None of Us Want to Stand Still

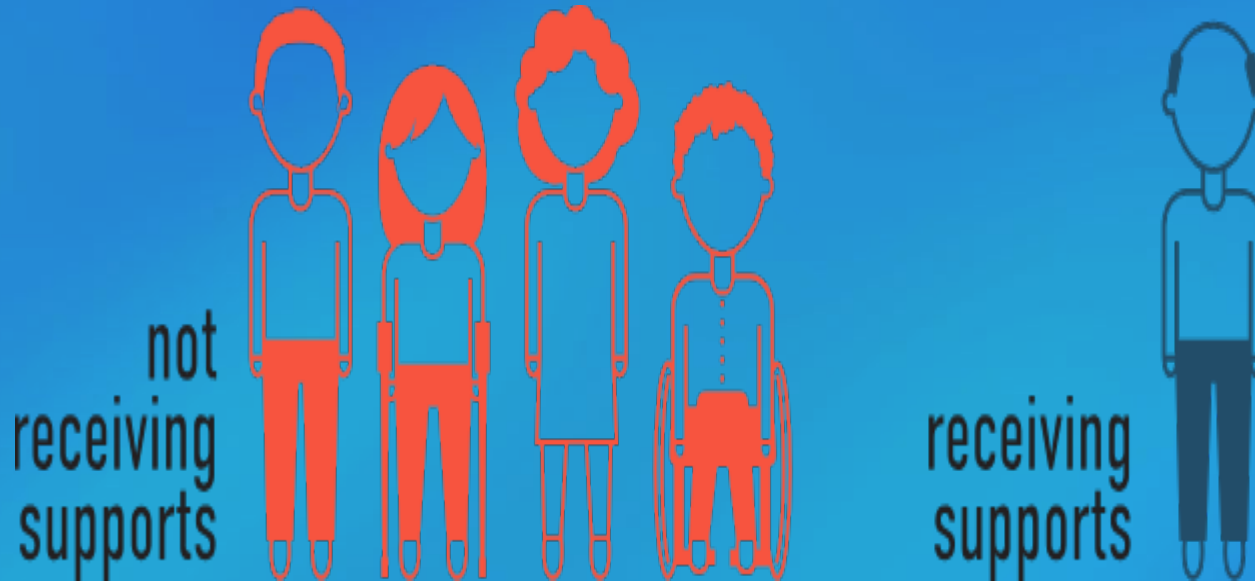
- Documentary on health care and IDD
- Voice to advocates to share their stories
- Examples of how changes can be made on all levels of a healthcare organization
- Produced by Rush University Medical Center and Georgetown University Center for Excellence in Developmental Disabilities.
- <https://vimeo.com/415331167>

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

Residential Information Systems Project (2024). Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from: <https://risp.umn.edu>.)

- More likely to live with parents (24% lives with caregivers 60 and over)
- Often need LTSS life-long
- Long waiting list for Home and Community Based Services (HCBS) waivers (497,354 in FY2019)
- Families and persons with disabilities need to engage in future planning

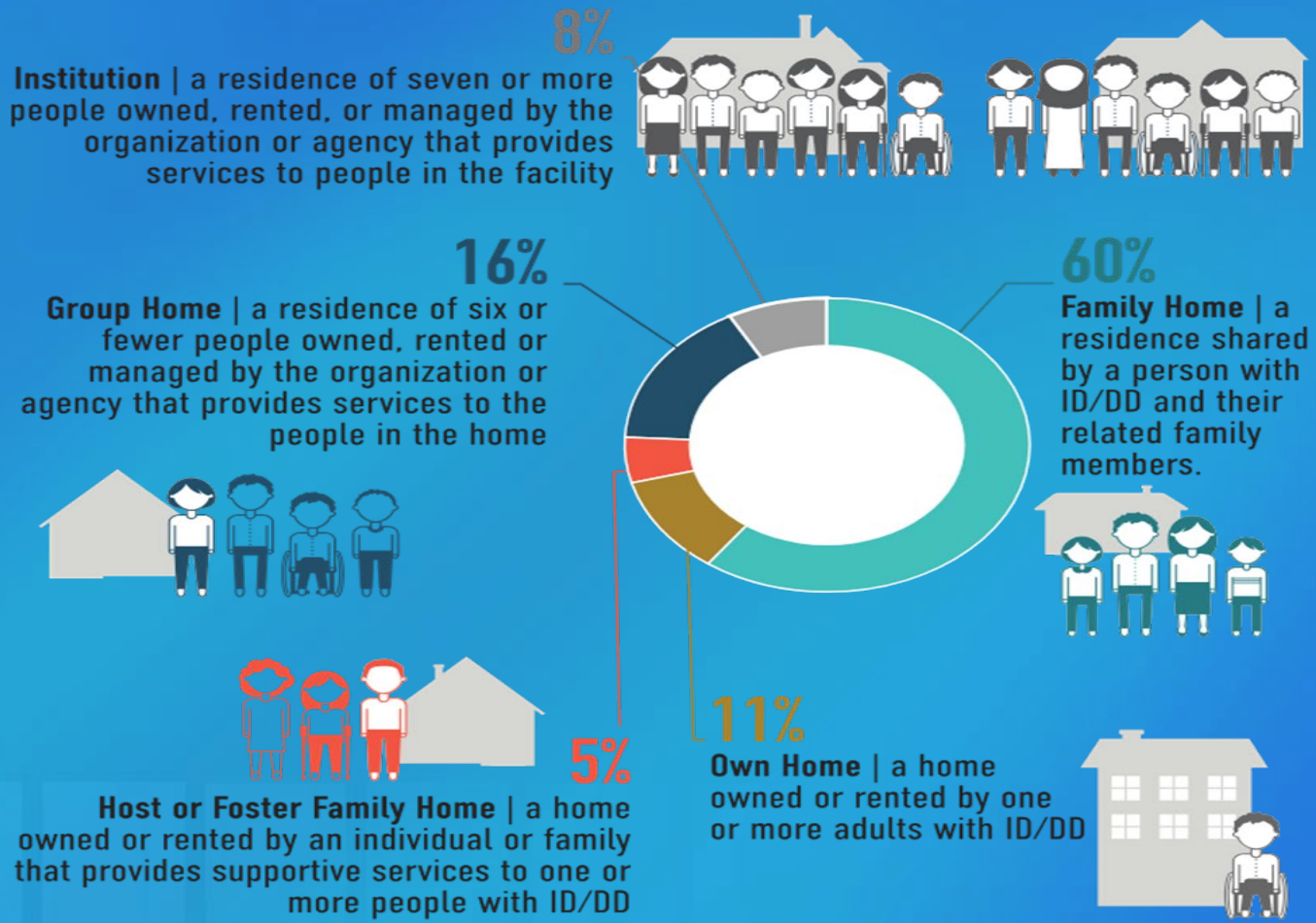
# Number of Families Receiving Support





# Where People Live

Residential Information Systems Project (2024). Minneapolis: University of Minnesota, RISP, Research and Training Center on Community Living, Institute on Community Integration. Retrieved from: <https://risp.umn.edu>.)





# 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

# Unmet Family Support Needs: Adulthood and Aging

- Role of families more formalized in schools unlike adult systems of care
- Unmet service support needs reported by families
  - Over 2/3 needed respite (73%), meal services (72%), and support groups (72%)
  - Over half needed training or education for future planning (63%) and home modifications (60%) and about half needed home healthcare (50%) and assistive technology (47%) (Crabb, Owen, & Heller, 2021).

# Family Support Makes Public Health and Financial Sense!

- Over 28% of extra costs for families caring for a person with a disability (Goodman et. Al, 2020)
- Family support associated with better family quality of life, more caregiving satisfaction, less stress and caregiving burden, and more self-efficacy in helping the family member with a disability (Crabb, Owen, & Heller, 2021; Kyzar et al., 2012)
- Unmet service needs associated with decreased mental health for female family carers of adults with IDD (Caldwell, 2008) and institutionalization (Heller & Caldwell, 2005)
- Psychoeducation interventions have shown positive impacts for families of individuals with IDD (Heller & Schindler, 2009).

# How Can We Support Families?

- Public Policies: governmental support
  - Cash subsidies
  - Consumer-directed supports
- Psychosocial Interventions
  - Support groups
  - Future planning
  - Support coordination
- Natural community and informal supports

# Need to Plan for Future Needs

- Many families do not make plans and experience barriers:
  - Unaware of legal and financial options
  - Fears for the future and unknown
  - Difficulty identifying caregiving support for the future
  - Difficulty in initiating the process
  - Have little contact with and mistrust formal disability services
  - Lack of aging and disability service system collaboration
  - Age-related needs and daily demands

# 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.





# Family Support Intervention: 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 and document
  - 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





# 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
- Virtual training developed (VFIN)

# Transition From In-Person to Virtual

## Future is Now: VFIN

- Virtual train the trainer in 8 states with the Arc (Owen et al., 2021)
- VFIN using Zoom for real time interactive sessions.
  - Conducted in KA, IL, CA
  - 15 trainers , 1000 participants in CA
  - Spanish version also
- Family Support Research and Training Center VFIN
- <https://ahs.uic.edu/disability-human-development/lifespan-health-community-living-and-intellectual-developmental-disabilities-research-and-training-programs/virtual-future-is-now/>
- <https://futureplanning.thearc.org/>



# Family Ties: Siblings as Longest Lasting Relationship



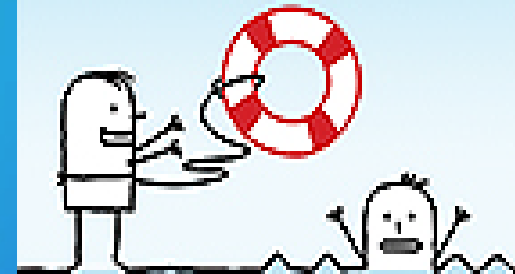
# Sibling Leadership Network

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

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



## The Sibling Survival Guide



Indispensable Information  
for Brothers and Sisters of  
Adults with Disabilities

Edited by Don Meyer & Emily Holt  
Foreword by Rachel Simon



# Need for Bridging Aging and Disability

- Contribute to each other
- 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)
- **Aging in Place, Aging in Community, Disability and Aging Friendly Communities**



# Bridging Aging and Disabilities Initiatives

- Bridging Aging and Disability (National Association of Councils on Developmental Disabilities)

<https://nacdd.org/bridging-aging-disability/>

- 17 state projects
- Emerging and Promising Practices report
  - Information, Referral, Navigation (cross training, No Wrong Door)
  - Connecting and Networking (e.g., peer support, future planning)
  - Services and Policy (e.g., disaster preparedness, change in guardianship, change in intake form)

# National Task Group on ID and Dementia Practices

- NTG Model Training Curriculum on ID and Dementia
- 3 day workshops on dementia in 17 states with 1300 support workers with 500 staff using curriculum
- Family Caregiver Webinar Series on ID and Dementia (<https://www.the-ntg.org/family-caregivers>)
- On-line support group and newsletter for families
- Caregiver's guide for families in Rhode Island
- *Supporting People with IDD/Aging/Dementia: Screening, Support Adaptation and Access to a Support Network and Autism, Aging, and Dementia: A consensus report of the Autism/Dementia 2<sup>nd</sup> International Summit on ID and Dementia*
- <https://www.the-ntg.org/>

# 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 the US Administration for Community Living, National Institute on Disability, Independent Living and Rehabilitation Research grants #s 90PTGE0006 (Family Support Research and Training Center on Bridging Aging and Disability), 901FRE0051 (Virtual Future is Now), and by the National Association of Councils on Developmental Disabilities 90DNCE009 (Bridging Aging and Disability).

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