

Webinar 3: Engaging with Aging in the Future Planning Process

Supported by the Texas A & M and
Texas Council for Developmental Disabilities

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July 27, 2022

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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?

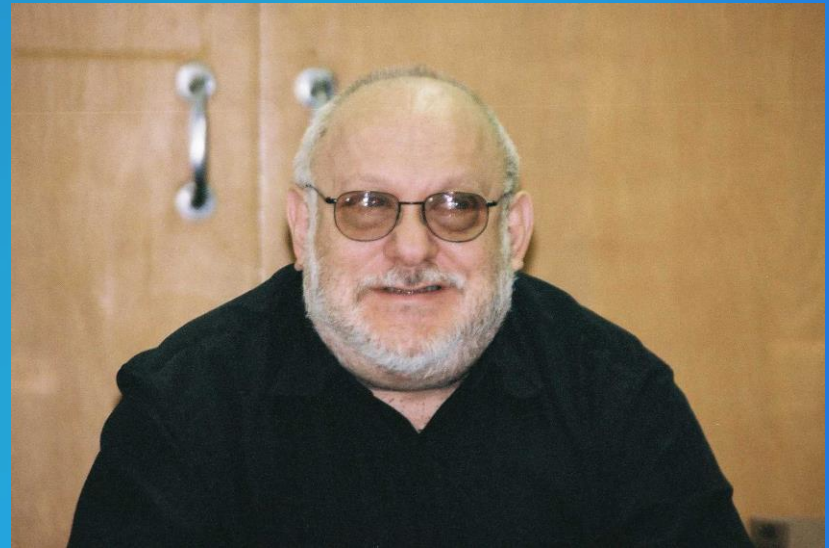
- **Aging without a disability?**
 - Ableism
- **Staying youthful?**
 - Ageism
- **“Compulsory youthfulness”** (Gibbons, 2016)
 - Intersectionality with disability studies
 - Old disabled as “failures”, diminished worth
 - Depends on ones choice and effort (Rowe & Kahn, 1998)
 - What is the state’s responsibility?

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

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
- Taking Care of Health
- Where We Live
- Friendships & Community Supports
- Work, Volunteering, & Free Time
- End of Life Planning
- Review & Goal Setting



Key Aspects

- Increase understanding of aging and context
- Choice making and self-determination in context of support systems
- Increase awareness of potential activities and actions
- Use of problem-solving and action planning

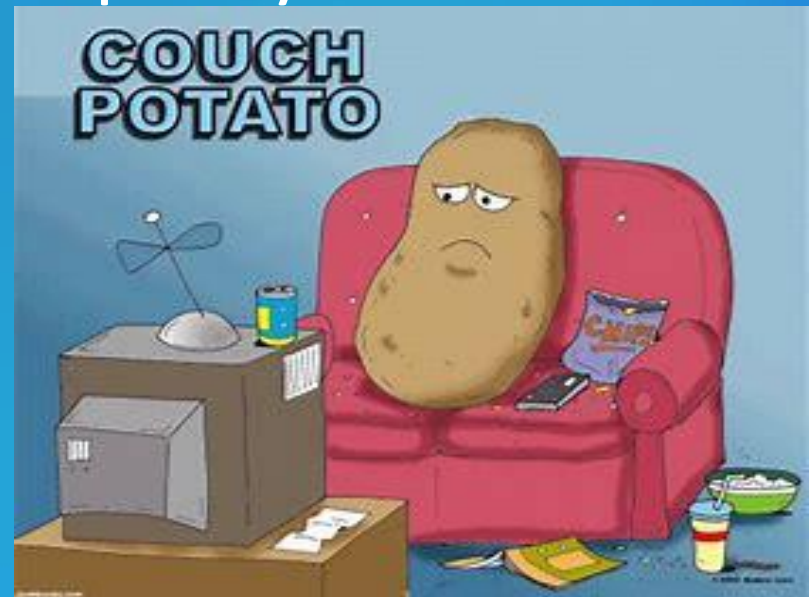
Health of People with IDD

- **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

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

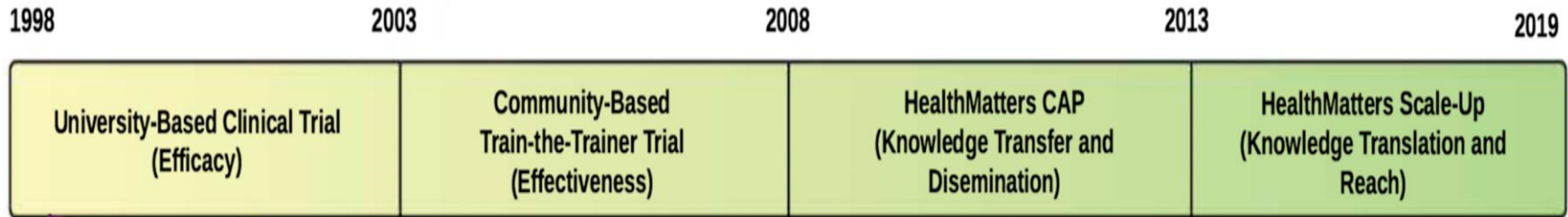


Better health and fitness in later life

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

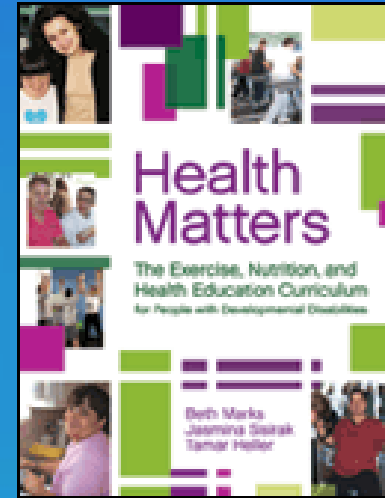
[HealthMatters Program.org](http://HealthMattersProgram.org)

Statewide Affiliates and Conferences

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

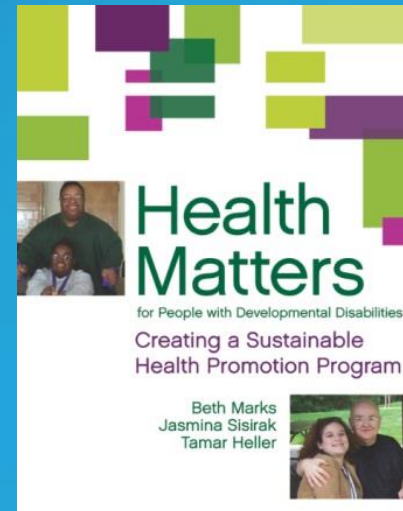
HealthMatters™ Program Intervention

- 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.

- Virtual Future is Now

www.HealthMattersProgram.org

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"



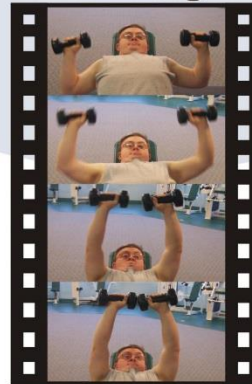
Maintenance

"I'm making plans"

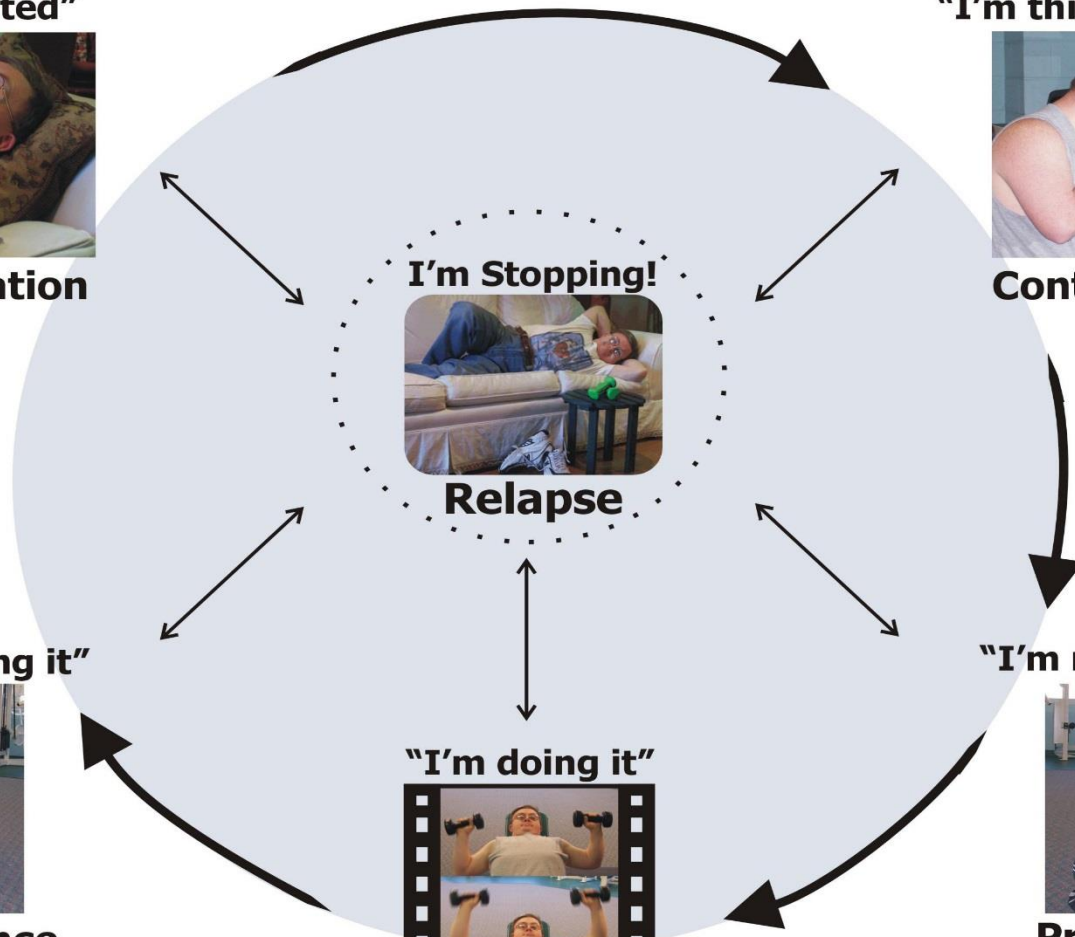


Preparation

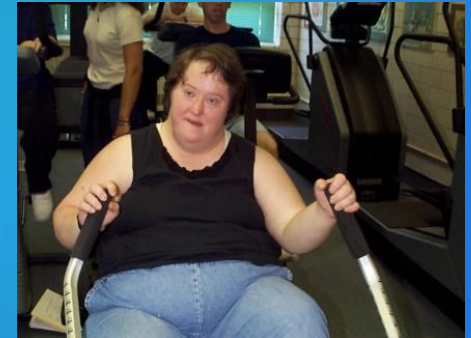
"I'm doing it"



Action

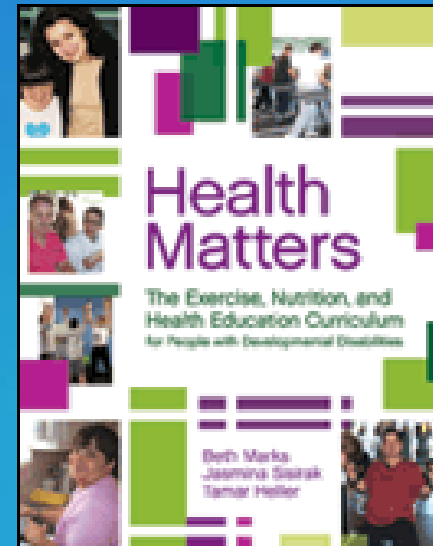


Fitness Classes



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

Prior to Start of Program

- 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

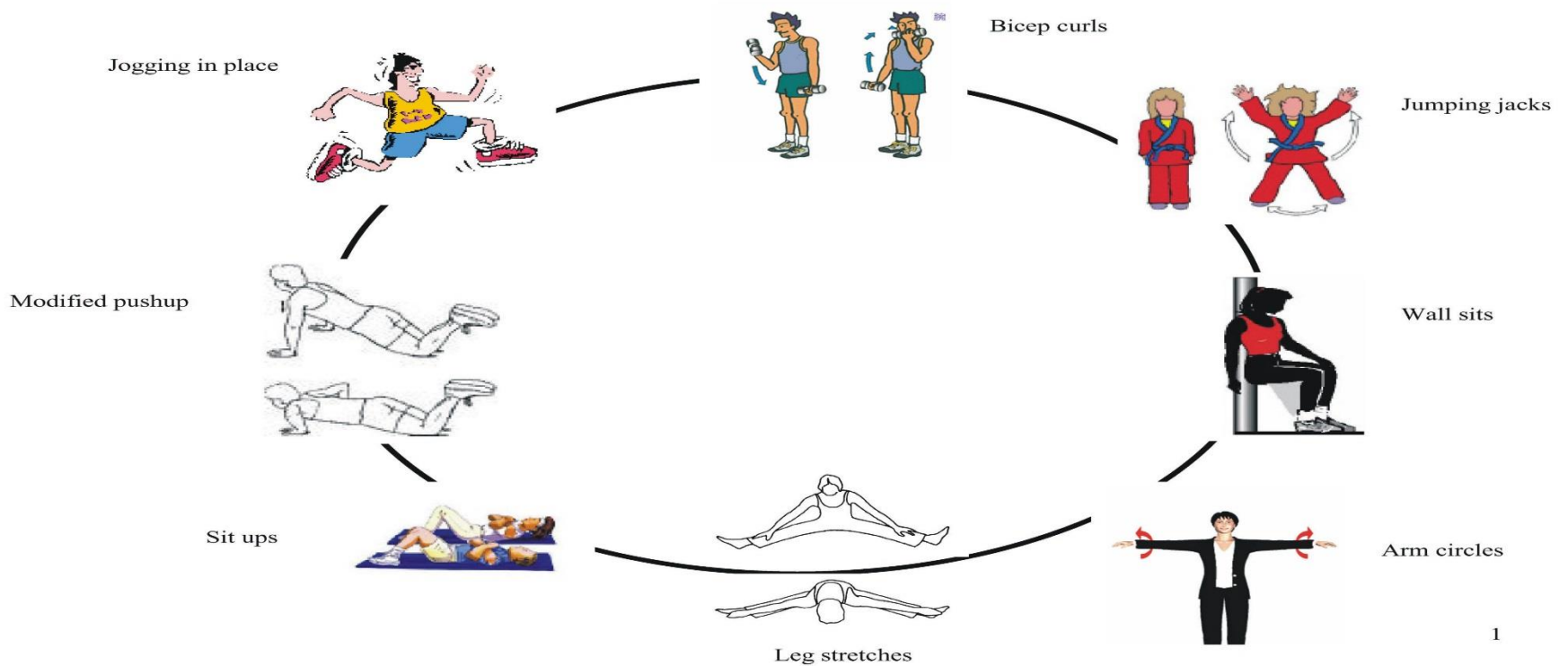
↑↑ physical activity, strength &
energy, Peak VO₂, & stair
climbing

↑↑ caregiver perception
of exercise benefits

↓↓ Access barriers

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 Findings

- 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.”*

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
<https://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 the letter 'H'. Below this is a yellow warning box with exclamation marks 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 sections: 1. A box for personal information with fields for '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 this box is a circular placeholder with the text 'Attach your picture here!'. 2. A paragraph of text: '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'. 3. A line for 'My signature: _____' and 'Date completed: / /'. 4. A line for 'You can talk to this person about my health: _____' and 'Phone number: _____' and 'Relationship: _____'. 5. A box with a 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 several blank 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>

Planning for Living Arrangements

- Aging of caregivers
- Changes in family situation
- Options in the community
- Roles after placement

Texas Place of Residence 2018

Select a state or the U.S.:
Texas

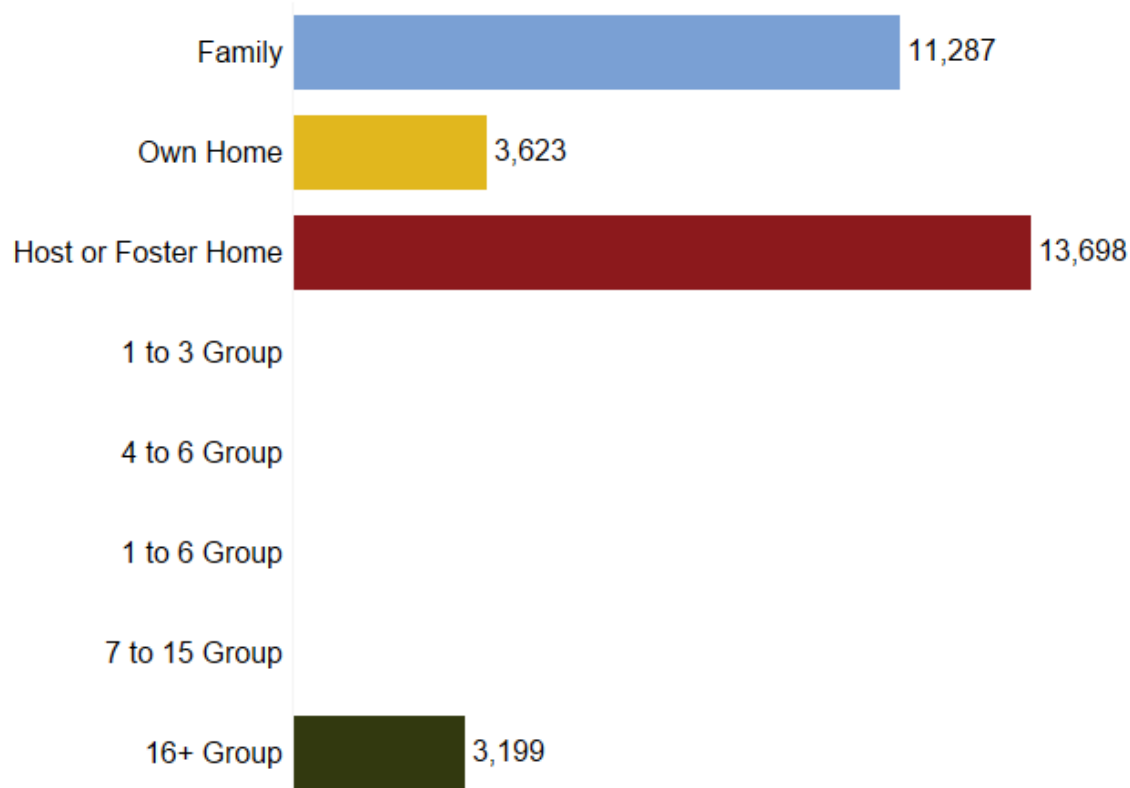
Select year:
2018

Click on a bar to view data. Data may not be available for all years. Download options on lower right.

Texas

Long-Term Supports and Services (LTSS) Recipients
Fiscal Year 2018

Group settings (1-6, 7-15, and 16+) include ICF/IID, group homes, and other congregate settings.



Employment and Retirement

- IDD employment (The National Survey of State IDD Agencies' Employment and Day Services)
 - 6% in TX vs 15% in integrated paid job
 - 94% in TX in facility based non-work
 - 50% would like job (NCI 2020-2021)
 - 17% in US do not want job since they are retired
- Mostly in facility based and non-work setting (Winsor et al., 2017)- retirement options (e.g., 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)

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**
- **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

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
 - 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

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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