

# HealthMatters for People with IDD: Building Communities of Practice for Health Research to Practice

The AUCD and  
RRTCDD Webinar

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**HealthMatters™**  
*Inform, Educate, and Empower*  
[www.HealthMattersProgram.org](http://www.HealthMattersProgram.org)



# Real People

People with IDD have an increased risk of chronic disease



- Experience poorer health status than their peers without disabilities.
- Minimal to no access to **physical activities**, restricted opportunities to learn how to **engage in fitness**, and have diets often **devoid of fruits and vegetables**.
- More likely to be obese or morbidly obese as compared to adults without IDD.

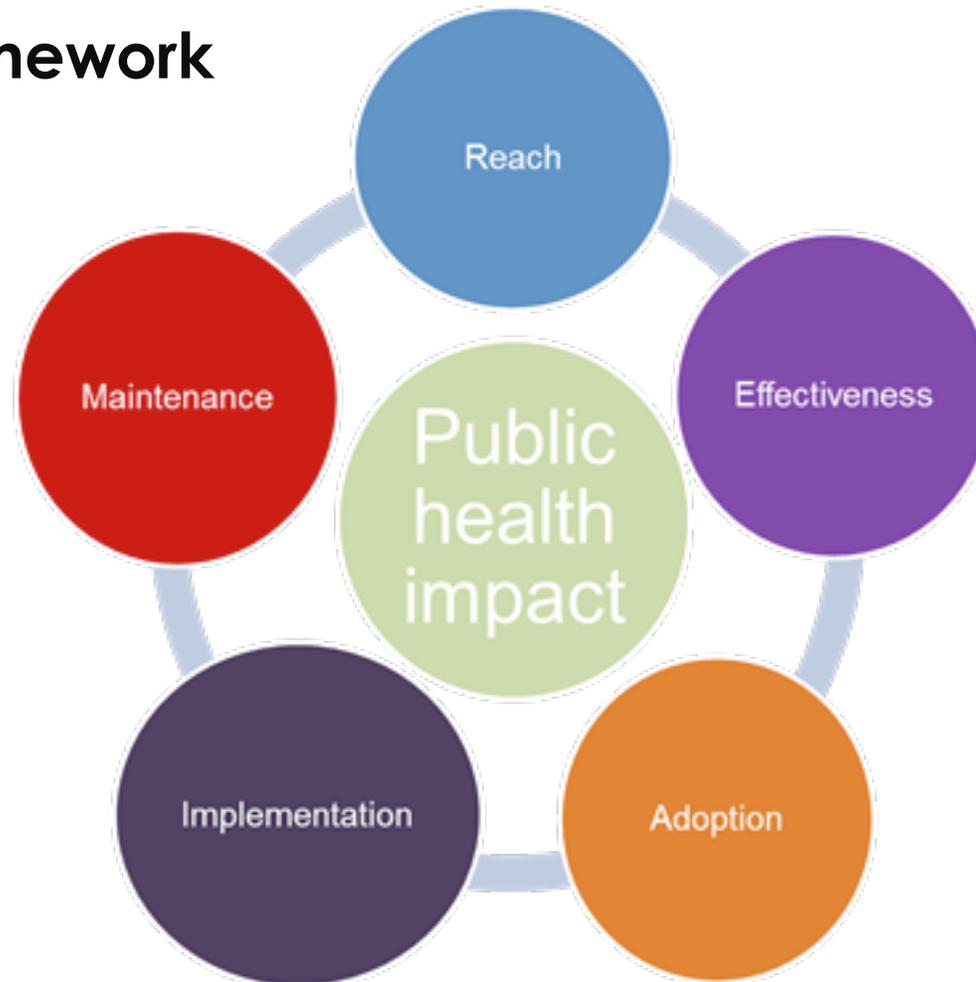
# Building Communities of Practice for Health

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- **HealthMatters™ Program Initiative** – evidence-based health promotion program for people with IDD (Alaska, Illinois, Kentucky, Maryland & Missouri).
- **Access to healthy lifestyle** opportunities to improve health behaviors and health status where people live, work, learn, and play.
- **Enhanced organizational and community capacity** to support people with IDD to incorporate healthy lifestyle into daily living.

# Translating Research into Action

## RE-AIM Framework



Glasgow, Vogt, & Boles, 1999

Image, University of California, CalFresh 3

# HealthMatters Program Initiative

## Partners

### State Coordinators for *HealthMatters Initiative*

<b>Alaska</b>	<u>University of Alaska Anchorage Center for Human Development (UCEDD), endorsed by the Alaska Health and Disability Program, Department of Health and Human Services</u>
<b>Illinois</b>	<u>Institute on Disability and Human Development, University of Illinois at Chicago (UCEDD), Illinois Disability and Health Program at the Illinois Department of Public Health</u>
<b>Kentucky</b>	<u>Human Development Institute at the University of Kentucky (UCEDD) and Kentucky Division of Developmental and Intellectual Disabilities</u>
<b>Maryland</b>	<u>Maryland Department of Disabilities</u>
<b>Missouri</b>	<u>University of Missouri - Kansas City (UMKC) Institute for Human Development (UCEDD) and <b>eitas</b> - Developmental Disability Services of Jackson County</u>

# Reach – Awareness Campaign

1. Announcements via social media, listservs, presentations
2. RapidHMA survey (online) to assess CBO's health promotion programs and services infrastructure, environmental supports, resources, and culture
3. Getting the Memo webinar

## Percent of CBOs in each Stage of Change for Health Promotion in HealthMatters Initiative Reach across four states (AK, IL, KY, MO) n=217

<b>Precontemplation</b> (CBO currently <b>does not</b> have health promotion program for people with IDD)	36%
<b>Contemplation</b> (CBO <b>intends to start</b> a health promotion program in <b>the next 6 months</b> )	29%
<b>Preparation</b> (CBO <b>intends to start</b> a health promotion program in <b>the next 30 days</b> )	3%
<b>Action</b> (CBO currently <b>has health</b> promotion program)	4%
<b>Maintenance</b> (CBO <b>has</b> been offering health promotion program for at least <b>6 months</b> )	26%

# Adoption – Developing Capacity and Support

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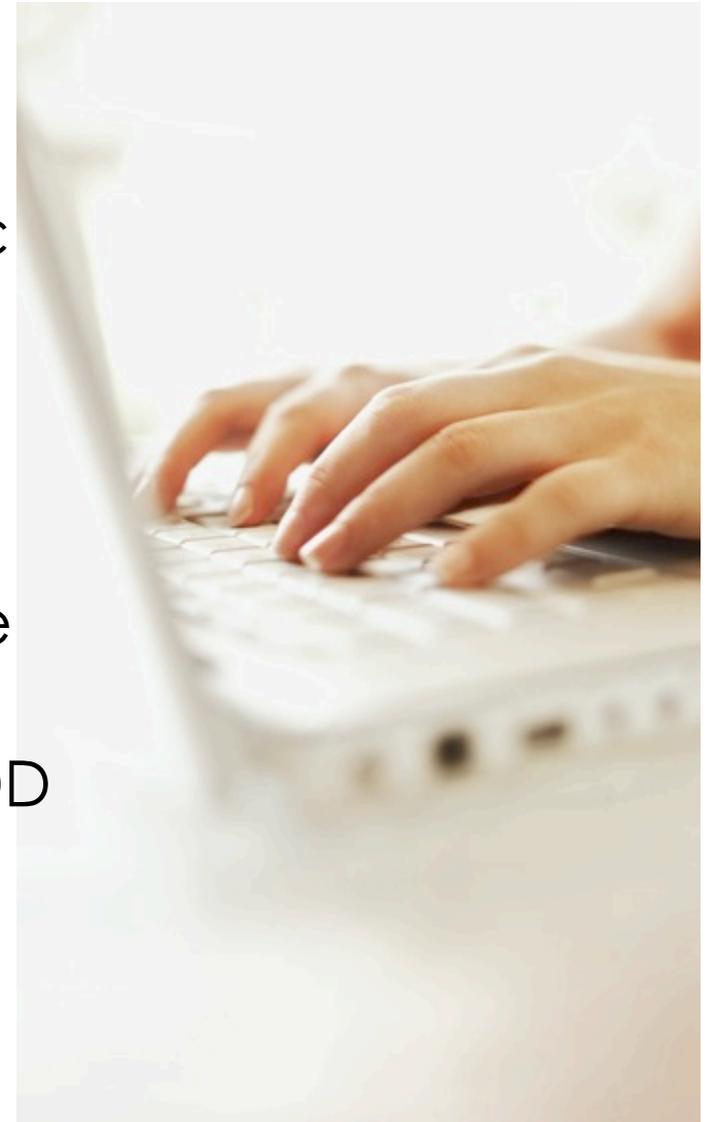
1. **Submit application** that supports CBOs to develop a strategic action plan for health and wellness
2. **Establish CBO HealthMatters Team** of at least three members including a team coordinator
3. **Identify current partnerships** for health promotion programming with other local community organizations
4. **Sign letter of Interest** to demonstrate their understanding and acceptance of the program commitments
5. **Form Wellness Committee** (if not in place)
6. **Complete** Organizational *HealthMatters Assessments* survey (25%)



# Implementation – Train the Trainer Certified Instructor Webinar

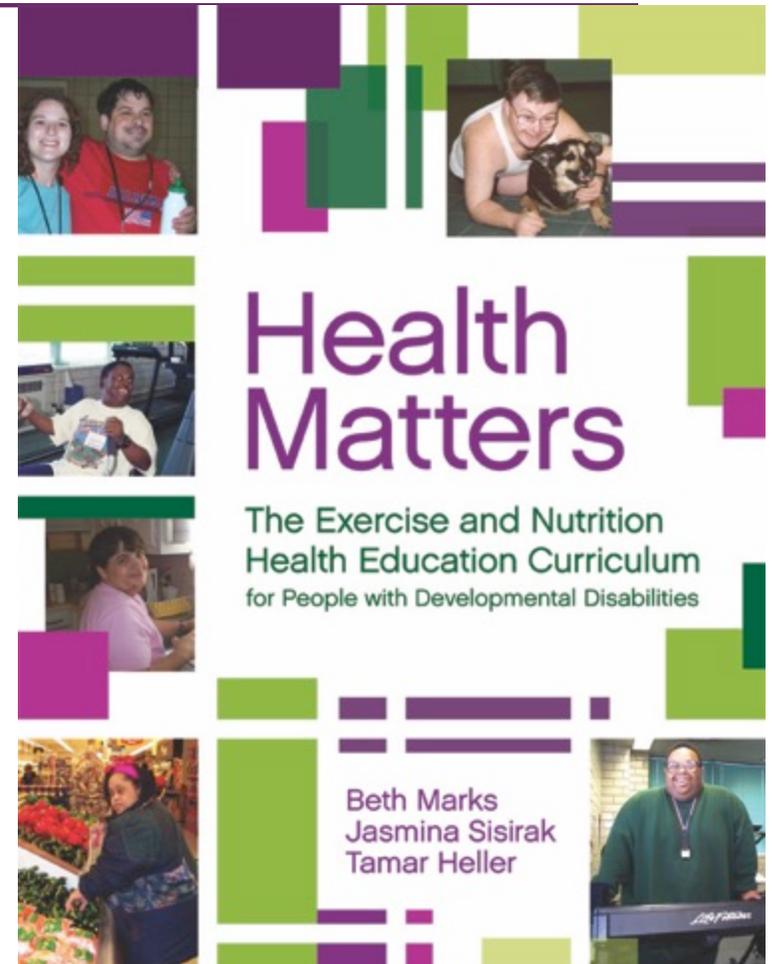
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- 3 staff (*HealthMatters Team*)
- Three 90 minute live webinars
  - **Develop** Organizational Strategic Action Plan for Health
  - **Develop and teach** a physical activity and health education program for people with IDD to reach their health goals using the *Health Matters Curriculum*.
  - **Assist and support** people with IDD to develop health promotion goal(s) and make long-term lifestyle changes.



# Implementation – 12-Week HealthMatters Program for People with IDD

- ❑ 12 weeks, 3x per week (4-6 hours)
- ❑ Customizable to meet CBO needs
- ❑ *Health Matters: Exercise and Nutrition Health Education Curriculum for People with DD*
  - ❖ 36 interactive modules
  - ❖ 23 additional lifelong learning modules



Marks, Sisirak, & Heller (2010). *Health Matters: The Exercise, Nutrition, and Health Education Curriculum for People With Developmental Disabilities*, Brooks Publishing., p. xii

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# Maintenance – Sustaining Health-Friendly Services

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- Final results in 2018
- 12 out of 16 (75%) CBOs continue their Wellness Committee and offer the *12-week HealthMatters Program* after 1 year
- Individual participant health goals are being added to the quality improvement plans
- Barriers
  - High staff turnover rates (continuous training)
  - Organizational mergers
  - Competing priorities

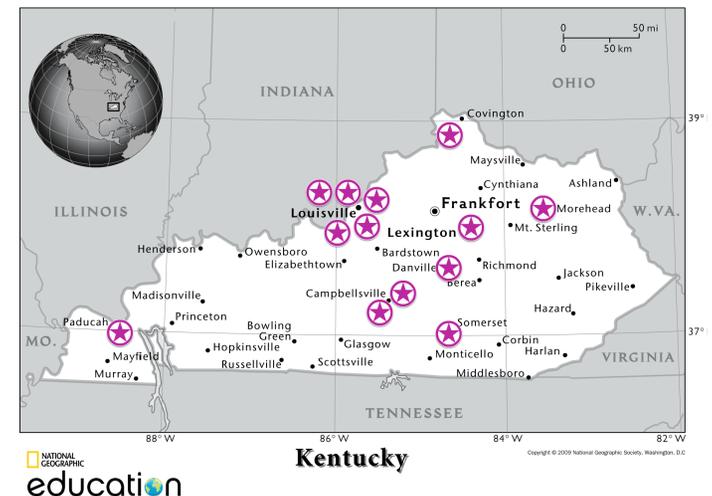
# HealthMatters™ Program

## KENTUCKY

- ❑ 2013 Partnership with Human Development Institute at University of Kentucky, HDI (Kentucky UCEDD) and Kentucky Division of Developmental and Intellectual Disabilities (DDID)
- ❑ 19 CBOs participating in the Initiative
- ❑ 10 CBOs continue offering the HealthMatters Program beyond the first 12 week session after 1 year (maintenance).
- ❑ 93 Certified Instructors
- ❑ 467 people with IDD participated in 12-Week *HealthMatters Program*



Human Development Institute  
University Center for Excellence in Developmental Disabilities





# HealthMatters™ Program KENTUCKY



- ❑ Organizational Culture
  - ❑ Staff Behavior Influence
  - ❑ Motivating Factors
  - ❑ Fundamental Shift in "the way we do things"
- ❑ Community Collaborations
  - ❑ Extension Offices
  - ❑ Farmers & Markets
  - ❑ Committees
- ❑ Universal Highlights
  - ❑ "Biggest Loser"
  - ❑ Gardening
  - ❑ Self-Advocacy & Self-Determination

*"If you are participating and giving your all, it's going to make them want to participate and give their all. . . it's not just with people with disabilities. It's for everybody. It made me feel and them feel important, that we mattered."*

– Sue (Staff Participant)

# HealthMatters, Kentucky! Interview with Stephen & Terry from Tri-Generations

The way I used to be  
By Stephen Love

I used to be as big as a tree  
Just like my whole family  
They would fill themselves with cakes and pies  
And never want to exercise  
When I wanted to lose weight  
They called me names and filled me with hate  
You're not going to lose weight you idiot  
You're going to be fat like us you twit  
But that drove me to work hard  
I pushed myself from the start  
I worked hard, fast, and quick  
I was losing weight by the look of it  
Now they look at me with pain

Hello, this is James Stephen Love, and this is my poem "The way I use to be".

You can do what you envision

You just need will and good motivation

0:08 / 5:14



Features the perspective of an administrative personnel and program participant from Tri-Generations in Somerset, Kentucky about their experience with the *HealthMatters* Program, Kentucky! and the life changing outcomes.

# Promising Practice and Policy Recommendations

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- ❑ **Recommendation 1 (R1):** *Establish State Communities of Practice for Health (CoP-H) for People with IDD and their Supports.*
- ❑ **Recommendation 2 (R2):** *Concretize community cross-sectoral collaboration.*
- ❑ **Recommendation 3 (R3):** *Track participation and outcome in health-related initiatives (primary care, health promotion, disease prevention).*
- ❑ **Recommendation 4 (R4):** *Create a “culture of health” within community-based organizations providing services for people with IDD.*

# ***R1: Establish State Communities of Practice for Health (CoP-H) for People with IDD and their Supports***

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Centrally coordinated:

- ❑ University Centers for Excellence in Developmental Disabilities (UCEDD)
- ❑ State Departments of Disabilities
- ❑ CDC's State Disability and Health Programs
- ❑ Associations on Developmental Disabilities/  
State Developmental Disabilities Councils
- ❑ The Arc HealthMeets

## R1, cont.

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- ❑ Identify the causes of health inequities for people with IDD on a local level and provide resources.
- ❑ Accelerate the translation of research findings to protect the health of people with IDD where they live, work, learn, and play.
- ❑ Include people with IDD in systematic approaches to social marketing, health education, and consumer research to develop communication strategies that inform and influence community decisions related to health for people with IDD.
- ❑ Leverage the Affordable Care Act (ACA) to develop incentives for wellness programs; and, to promote culturally and linguistically congruent employer-based wellness programs that encourage healthier workplaces and expand employer wellness programs to include people with disabilities.
- ❑ Include people with IDD within the [Executive Order 31544 – Establishing the National Prevention, Health Promotion, and Public Health Council.](#)

## R2: Concretize community cross-sectoral collaboration.

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- ❑ Establish collaborative efforts to eliminate silos between local CBOs serving people with IDD, local health departments, and other community sectors and to ensure accessible health programming, materials, and environments.
- ❑ Assess inclusivity of local and state programs materials.
- ❑ Integrate principles of Universal Design and Community Health Inclusion Index.
- ❑ Incorporate the Americans with Disabilities Act of 1990 (ADA) and the ADA Amendments Act of 2008 (ADAAA) across all community sectors.
- ❑ Add language to the Surgeon General's, *Step It Up!, the Call to Action on Walking and Walkable Communities* campaign to reference the barriers that people with disabilities face in accessing physical activity, along with identifying strategies to enhance walkable communities and the positive health benefits for people with disabilities.
- ❑ Partner with the *Let's Move* initiative to ensure accessible content, environments, and communication strategies for everyone including children and adolescents with IDD.

## **R3: Track participation and outcome in health-related initiatives (primary care, health promotion, disease prevention).**

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- ❑ Connect with large prospective investigations into the risk factors for major chronic diseases among people with IDD (e.g. Nurses Health Study, Framingham Heart Study, Surveillance, Epidemiology, and End Results (SEER) Program).
- ❑ Coordinate National Core Indicators efforts with *CoP-H HealthMatters Program Initiative*, to improve epidemiology and surveillance of participation, outcomes and available health related services among people with IDD.
- ❑ Establish *Information Exchange Networks* within *CoP-H*.
- ❑ Measure return on investment of health promotion programs for people with IDD and their supports.

## R4: Create a “culture of health” within community-based organizations providing services for people with IDD.

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- ❑ Review policies, mission and vision statements, job descriptions, trainings, and commitment to health and health promotion.
- ❑ Identify capacity for health promotion by creating a comprehensive inventory of programs and services within organization and local community.
- ❑ Communicate wellness as a part of long-term priority for organization.
- ❑ Establish health teams with a coordinator and organizational wellness committee to develop *Strategic Action Plan for Health*.
- ❑ Provide education and health promotion programs for employees and people with IDD.
- ❑ Market “*health-friendly services*” to model “*access and inclusion in action*” across local community sectors (e.g. education, employment, recreation).

# Questions

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- Email us: [info@healthmattersprogram.org](mailto:info@healthmattersprogram.org)
- Visit [www.HealthMattersProgram.org](http://www.HealthMattersProgram.org)

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