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# Research to Policy Brief

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## *HealthMatters for People with Intellectual and Developmental Disabilities: Building Communities of Practice for Health*


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The emergence of accessible health promotion initiatives for people with intellectual and developmental disabilities (IDD) over the past 20 years demonstrates great promise for improving their health status. However, people with IDD continue to experience numerous age-related health issues and often lack control over environments and practices that impact their health. Just as in the general U.S. population, a great challenge remains to lower obesity levels, increase physical activity, and improve diets among people with IDD [1-5].

While research evidence for successful population specific health promotion programs and training, such as the *12-Week HealthMatters Program* has been documented, [6-10] an urgent need exists for widespread translation of evidence-based programs into practice and policy implementation. The next step is to develop and test models to support changes in state and community based organizations' (CBOs) policies and fiscal budgets that embed and sustain evidence-based health promotion programs in the communities where people with IDD live, work, and play. Determining successful scale-up processes of "what works" is critical in being able to achieve the goal of improved lives for the greatest number of people [11].

### Communities of Practice for Health (CoP-H): Toward Unified Health Promotion

Across the U.S., CBOs are providing care management and service delivery to people with IDD and have a pivotal role in implementing health promotion programs. CBOs can influence state and national policy decisions for health promotion activities and ensure implementation and sustainability of health-related programs with adequate fiscal and infrastructural resources – where the "rubber meets the road." Despite national and state reports detailing the benefits of targeted health promotion programs to reduce health disparities among people with IDD, a crisis is imminent across the country as under-trained support persons are charged with the increasing responsibility of managing healthcare needs of people with IDD across their lifespan.

People in our communities, including healthcare professionals and institutions, families, people with disabilities, schools, and recreational facilities rely heavily on CBOs to fill the existing gaps in a taxed health

HealthMatters™ Program

care delivery system plagued by "silos" of care. CBOs have a natural and much needed role, as they are often the sole informed and experienced advocates for people with IDD and their supports. CBOs are centrally rooted in communities with linkages to local, state, and federal policymakers. To fulfill this natural role, CBOs need to build capacity and infrastructure through defined mission, vision, written policies, and job descriptions to support health promotion and secure the support of local, state, and federal fiscal and policy stakeholders. While many CBOs cannot assume this responsibility alone, Communities of Practice for Health (CoP-H) offer a structure to capture and transfer best practices [12] with state partners, local CBOs, families, and individuals with IDD.

CoP-H can integrate collective efforts to problem solve, provide best practices, offer expertise, share assets, coordinate and organize, map knowledge, and identify gaps in health services for people with IDD [13]. Sufficient capacity and commitment among stakeholders across multiple constituencies is imperative for achieving integrated community-based health promoting activities. Successful implementation also requires examination of contextual factors within each local situation to determine the unique multifactorial pathways for health promotion across all community sectors to support health for people with IDD [14, 15]. Identifying the contextual factors in each local situation is complex, as each community [16] may have distinct demographic profiles, political cultures, organizational characteristics, fiscal policies, and direct support professionals, all of which impact revenues, programmatic trends, and spending patterns.

## *HealthMatters Scale-Up Initiative*

*HealthMatters Scale-Up Initiative* is a 5-year project funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) that is currently testing an ecological framework to illustrate pathways and to establish Communities of Practice for Health (CoP-H) across five states – Alaska, Kentucky, Illinois, Maryland and Missouri. Please see **Table 1** for State Coordinators for the Initiative. Each state is in a different stage of the initiative with Kentucky being the first partner starting in 2013 and Maryland the most recent. The initiative is organizing the facilitating "drivers" to scale-up health promotion programming in each state, evaluating processes, building health promotion capacity in participating CBOs, training CBO staff, and providing evidence-based programming for people with IDD. *HealthMatters Initiative* aims to achieve widespread transformation of policy, fiscal budgets, and services to support health promotion initiatives for people with IDD and their caregivers through reach, adoption, implementation, maintenance using the evidence-based *HealthMatters Train the Trainer Program for Instructors* and the *12-Week HealthMatters Program for People with IDD* across three levels within each state:

1. fiscal and policy capacity supporting health and wellness (e.g. CBOs, local communities, states);
2. community and organizational capacity for Health-Friendly Services; and,
3. attainment of health goals and improved health status among people with IDD where they live, learn, work, and play.

The HealthMatters Initiative leverages ***HealthMatters Train the Trainer Program for Instructors*** and the ***12-Week HealthMatters Program for People with IDD*** to build capacity for creating health-friendly services and to develop a collaborative between CBOs and fiscal/policy stakeholders.

## Highlights of Emerging Findings for the *HealthMatters Scale-Up Initiative*

### *HealthMatters Initiative Scale-Up Pathways:*

#### STEP 1- Partnership

Coordinate statewide health promotion initiative partnerships through each state. **Table 1** identifies current State Coordinators/Partners of the HealthMatters Initiative.

#### STEP 2 – Reach

Initiate a statewide HealthMatters Initiative awareness campaign through the state Network. This includes provider listservs and social media announcements describing the HealthMatters Initiative. As part of the larger awareness building campaign and to determine CBO interest in health promotion programming, web-based organizational-level questionnaire, RapidHMA

**Table 1. State Coordinators for *HealthMatters Initiative***

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

[17] is conducted. RapidHMA is designed to assess CBO's health promotion programs and services infrastructure, environmental supports, resources, and culture. The survey also includes stage of change algorithms for health promotion. Two hundred and seventeen (217) CBOs participated in the RapidHMA survey across four states (Alaska, Illinois, Kentucky, and Missouri). **Table 2** shows stages of readiness to adopt health promotion services for people with IDD in CBOs across all of the four states. Sixty-four percent (64%) either had no health promotion programs or they were thinking about starting a program. Twenty-six percent (26%) of CBOs reported that they had been offering health promotion programs for over 6 months. The results of the RapidHMA survey are presented in a statewide "Getting the Memo" webinar. The webinar introduces HealthMatters Initiative, the team, delineates application process, timeline, and the steps of the initiative.

### STEP 3 – Adoption

Secure buy-in within self-selected CBOs through an application process that (1) supports CBOs to develop a strategic action plan for health and wellness, (2) creates a CBO HealthMatters Team of at least three members including a team coordinator, (3) describes current partnerships for health promotion programming with other local community organizations, (4) signs a Letter of Interest to demonstrate their understanding and acceptance of the program commitments, (5) establishes a wellness committee (if not in place), and (6) completes an organizational HealthMatters Assessments survey [17]. Forty CBOs are currently participating in the Initiative and have completed the above steps (**Table 3**).

### STEP 4 – Implementation

Attend three 90-minute HealthMatters Program Train the Trainer Webinars, develop a Strategic Action Plan for Health and Wellness and implement at least one 12-Week HealthMatters Program for 6-8 participants with IDD and an optional program evaluation using an online pre- and post-survey. The evaluation includes measures of health behaviors, nutrition and activity knowledge, confidence to exercise, supports for exercise and nutrition, as well as National Core Indicators wellness domains (BMI, engagement in moderate physical activity, smoking, exercise) (see www.nationalcoreindicators.org).
To date, 226 support staff attended HealthMatters Program Train the Trainer Webinars and 820 people with IDD have participated or are participating in the 12-Week HealthMatters Program (**Table 3**).

### STEP 5 – Maintenance

Sustain Health-Friendly Services by integrating evidence-based programs through practices and policies that are institutionalized within CBOs and state after 6 or more months. While final results of the Initiative will not be available until 2018, emerging/preliminary research findings demonstrate that 12 (75%) CBOs (out of 16 that have completed 1 year Initiative) continue with their Wellness Committee meetings and offer the 12-week HealthMatters Program. Individual participant health goals are being added to the quality improvement plans so that the client-directed desirable health outcomes are focused on as an important component of positive supports and those supports held accountable for providing appropriate resources. Wellness Committees continue to meet and are expanding goals and wellness activities (e.g. offering cooking and nutrition demonstrations, creating raised garden beds, establishing local community walking groups, developing partnerships with local farms and farmers markets for fresh produce, changing vending choices for healthier options). Agencywide health promotion activities include both people served and employees.

Programs are developed with fun in mind and focus on improved nutrition and increased physical activity.

**Table 2. Percent of CBOs in each Stage of Change for Health Promotion in *HealthMatters Initiative* Reach Across Four States**

| Stage of Change [18] | Percent (%) |
|---|---|
| **Precontemplation** (has no health promotion program for people with IDD) | 36 |
| **Contemplation** (intends to start a health promotion program in the next 6 months) | 29 |
| **Preparation** (intends to start a health promotion program in the next 30 days) | 3 |
| **Action** (has health promotion program) | 4 |
| **Maintenance** (has been offering health promotion program for at least 6 months) | 26 |

## Promising Practice and Policy Recommendations

As results are still emerging and to address the issue of scalability of health promotion efforts to improve health outcomes for people with IDD, four practice and policy recommendations have been identified.

### RECOMMENDATION 1: *Establish Statewide Communities of Practice for Health (CoP-H) for people with IDD and their supports.*

**Rationale:** Enhance translation of research to policy to practice. The CDC's 2009 report The Power of Prevention Chronic disease . . . the public health challenge of the 21st century states that "Promising research findings are relevant only when they reach the people they are designed to serve" [19]. Adopting CoP-H across the country can ensure that scientific findings are put into practice and evaluated within state and local health policies. CoP-H initiatives such as the *HealthMatters Program* can be centrally coordinated within various networks to provide comprehensive health, health promotion, disease prevention programs to reduce health disparities and improve health status among people with IDD and their supports such as the following:

1. University Centers for Excellence in Developmental Disabilities (See national map at www.aucd.org);
2. State Departments of Disabilities;
3. CDC's State Disability and Health Programs (www.cdc.gov/ncbddd/disabilityandhealth/programs.html);
4. Associations on Developmental Disabilities/State Developmental Disabilities Councils; and,
5. The *Arc HealthMeet® (http://www.thearc.org/healthmeet*.

**Action Steps:**

- Identify the causes of health inequities for people with IDD on a local level and provide resources for people with IDD to access primary care and health promotion and disease prevention services.
- 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) [20, 21] 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. ACA provides a framework for the Health Homes through CBOs. CBOs can coordinate care and ensure that health promotion, disease prevention, and primary care are compliant with ADA and that services are linguistically and culturally congruent.
- Include people with IDD within the "Executive Order 31544 – Establishing the National Prevention, Health Promotion, and Public Health Council" within the Department of Health and Human Services to to promote accessible content, environments, and linguistically and culturally congruent communication for everyone.

### RECOMMENDATION 2*: Concretize community cross-sectoral collaboration.*

**Rationale:** Improve communication, services, programs, and materials. Cross-sectoral collaboration supports the development of practical solutions to solving local social concerns. Ongoing collaboration across community sectors and state entities can

ensure that implementation of health promotion programming for people with IDD is efficient and effective. The inclusion of people with IDD in all community-based health promotion programs can create accessible activities and environments and promote positive health outcomes for all community members across the lifespan.

**Action Steps:**

- 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 local and state programs, services, and materials related to health, health promotion, disease prevention to ensure inclusive language for reaching people with IDD and other disabilities.
- Integrate principles of Universal Design and use the *Community Health Inclusion Index* [22] to include people with IDD who often have a myriad of physical, sensory, and psychiatric disabilities.
- 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 [23].
- Partner with the *Let's Move* initiative [25] to ensure accessible content, environments, and communication strategies for everyone including children and adolescents with IDD; and, to promote healthy lifestyles beginning in early childhood and make nutrition information useful to parents, healthy foods in schools, healthy food access, and increasing physical activity in school and in the community.
- Incorporate the Americans with Disabilities Act of 1990 (ADA) and the ADA Amendments Act of 2008 (ADAAA) [24] across all community sectors.

### RECOMMENDATION 3: *Track participation and outcome in health-related initiatives (primary care, health promotion, disease prevention).*

**Rationale:** Improve health surveillance, practice, and policies. Integrating surveillance data into practice, fiscal, and policy efforts can support the development of "health-friendly services" within CBOs serving people with IDD [25]. Implementing participation and outcome metrics can support CBOs, local health departments, and state entities to identify and map high-need areas that experience health disparities and align existing resources to meet these needs.

**Table 3. Adoption and Implementation of *HealthMatters Initiative* across Four States**

| CBOs | Support Staff | People with IDD |
|---|---|---|
| 40 | 226 | 820 |

**Action Steps:**

- Connect with large prospective studies into risk factors for 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 (www.nationalcoreindicators.org/) 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 [26] within CoP-H.
- Measure return on investment of health promotion programs for people with IDD and their supports.

### RECOMMENDATION 4: Create a "culture of health" within community-based organizations providing services for people with IDD.

**Rationale:** CBOs are key community leaders positioned to fill the existing gaps in health service delivery and advocacy for people with IDD. To successfully meet this role CBOs need to build their capacity and sustainability to create "health-friendly services" which will improve the health of people with IDD and their supports.

**Action Steps:**

- Review policies, mission, and vision statements, job descriptions, trainings, and commitment to health promotion.
- Identify capacity for health promotion by creating a comprehensive inventory of programs and services within organization and local

community (*HealthMatters Assessments* at http://healthmattersprogram.org/what/evaluation/).
- 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 for employees with IDD.
- Market "health-friendly services" to model "access and inclusion in action" across local community sectors (e.g. education, employment, recreation).

## Conclusion

The *HealthMatters Initiative* focuses on achieving widespread transformation of policy, fiscal budgets, and services to support health promotion initiatives for people with IDD and their caregivers. Through the emerging evidence found in the five initial states, the evidence shows the current scalability and success of the initiative. While this has increased health promotion within these states for many people with IDD, we must identify mechanisms to embed health promotion across all local, state, and federal health-related policies and fiscal budgets.

These policy recommendations and action steps will help guide communities to tailor their own action steps aimed at realizing *Communities of Practice for Health* for people with IDD. Collaborative efforts across multiple sectors can create linguistically and culturally congruent health-related services for people with IDD. Systematic transformations in healthcare services through Communities of Practice for Health can ensure social and environmental supports for healthy lifestyles among people with IDD. Staying healthy requires a collective effort, social support, and environments where healthy choices are made available and easy options to make. Feeling healthy is imperative for people with IDD to maximize self-determination, improve quality of life, and achieve personal goals and life aspirations.

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