Translating Evidence-Based Health Promotion Research to Practice and Policy: Health and Equity

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HealthMatters™ Program

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Community Engagement: What Matters

• Parity in health status and equity in health care services among people with intellectual and developmental disabilities (I/DD).

• Challenges in developing and implementing community-based health promotion programs.

• Strategies for scaling-up evidence-based programs in community sectors.
40 Year Gap

• Great progress with health promotion and disease prevention research in the general population.

• Translating this research into practice is often challenging.

• Research limited for people with disabilities.
HealthMatters Program:
Research to Practice

University-Based Clinical Trial
(Efficacy)

Community-Based-Train the-Trainer Trial
(Effectiveness)

HealthMatters CAP
(Translation and Reach)

1998

Ongoing Dissemination of
HealthMatters Train-the-Trainer: Certified Instructor Workshop
(> 2125 Basic Instructors in 70 CBOs in 21 States)

ARCA: Statewide Health Promotion CBO Training

NRI: Organizational Cultural Shift, Statewide Health Policy Initiatives

HealthMattersProgram.org

Statewide Affiliates and Conferences

HealthMatters™ Program
Knowledge Lost in Translation

- Information gap
  - Slow or no reach to people receiving services
  - Good questions are asked – but not reaching academia.

- Gaps for groups:
  - women
  - racial/ethnic minorities
  - other high-risk groups in the US healthcare system – people with disabilities

Disability and Health Status

While a large proportion of persons who are in bad health end up with a disability, a large number of people with disabilities end up with bad health.
Health Promotion

• **Enable people** *to take control over* and *to improve* their health.

• Build capacity within CBOs and communities:
  – **Access** to affordable and available health care.
  – **Acceptable** culturally relevant and satisfactory health care.
### Dispelling Myths...

#### Changing Attitudes

<table>
<thead>
<tr>
<th>Myths</th>
<th>Facts</th>
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<tbody>
<tr>
<td>- People with I/DD are <strong>sick</strong>.</td>
<td></td>
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<tr>
<td>- Chronic conditions (e.g., obesity, hypertension, diabetes) are <strong>disability related</strong>.</td>
<td></td>
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<tr>
<td>- Lifestyle habits are impossible to change.</td>
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<tr>
<td>- People with I/DD see themselves as <strong>healthy</strong>.</td>
<td></td>
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<tr>
<td>- Chronic conditions are <strong>lifestyle related</strong> (e.g., sedentary, poor diets, lack of opportunity).</td>
<td></td>
</tr>
<tr>
<td>- <strong>Health promotion strategies work!</strong></td>
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</table>
Community Partnerships: “Won’t-Take-Failure-for-an-answer”

1. Community ignored
2. Community placed
3. Community informed
4. Community as partners
Determining Health Needs and Interests

- Biological factors – syndrome and gender-related conditions
- Socio-economic and environmental issues
- Access to health care services and programs
  - Physical, attitudinal, programmatic, and communication/literacy
- Behavioral practices
Beyond Personal Health Practices

• Sustainable health promotion programs
  – “Point of View” for Health
  – Behaviors most often influenced by broader socio-environmental and economic factors
  – “Where the people are…”

• Community Coalitions
  – Social capital – sense of trust and long-term reciprocity
There has been a lack of bi-directionality (sort of) because your research is yours (rightly so) and our comments may be helpful to you or not, but may not have significant influence on your process in the end.

~ Leslie Hoelzel, Grant Manager, ARCA
## HealthMatters Program: Research Trials

<table>
<thead>
<tr>
<th>University-Based Program</th>
<th>Community-Based Program</th>
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<tbody>
<tr>
<td>Professional Led</td>
<td>Train-the-Trainer</td>
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</table>

**Adults with I/DD**

- ↑ exercise attitudes
- ↑ exercise self-efficacy
- ↑ exercise outcome expectations
- ↑ life satisfaction
- ↑ cardiovascular fitness, strength and endurance
- ↓ cognitive–emotional barriers

- ↑ perceived health behaviors
- ↑ exercise self-efficacy
- ↑ nutrition/activity knowledge
- ↑ cholesterol & glucose
- ↑ fitness (flexibility)
- ↑ exercise & nutrition socio-environmental supports

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Marks, Sisirak, Chang (2013)
• Bi-directional infrastructure for community-based, participatory
  – research
  – service learning
  – training

“...a research set-back or obstacle is not an occasion to accept “failure,” but a time to rethink premises and find another way forward

~ ~Richard E. Sclove, Madeleine L. Scammell, and Breena Holland
Matters of Support

– **Individuals with I/DD** (Intrapersonal)

– **Social Support** (Interpersonal)
  - Caregiver support
  - Peer support

– **Supportive Environments** (Organization, Community, Policy)

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Socio-Ecological Theory
Source: Golden, S. and Earp, J. (2012), Social ecological approaches to individuals and their contexts: twenty years of health education and behavior health promotion interventions.
What about staff?

• Caregiver stress and burnout linked to
  – poor health
  – emotional problems
  – unhealthy lifestyles
  – poor quality of life
  – marital and family problems
Occupational Hazards

• **Physical**
  
  - Ergonomic hazards from lifting and repetitive tasks, poor body mechanics, limited flexibility, falls, physical attacks, adverse effects from shift work.

• **Biologic**
  
  - Bacterial infections, viral infections, fungal infections, bloodborne pathogens (e.g., scabies, pinworm, pink eye, ringworm, lice).

• **Stress**
  
  - Physical and psychosocial induced (e.g., verbal threats from clients).
Support Employee Health Conditions

- Back Pain: 39.1%
- HTN: 15.6%
- Arthritis: 17.2%
- Diabetes: 9.4%

Marks, Sisirak, Chang, 2012
## Support Staff Health Behaviors

<table>
<thead>
<tr>
<th>Variables</th>
<th>Intervention group (n=28)</th>
<th>Comparison group (n=20)</th>
<th>F value</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Pretest Mean (SD)</td>
<td>Posttest Mean (SD)</td>
<td></td>
</tr>
<tr>
<td>Socio-Environmental Supports for Nutrition</td>
<td>17.89 (6.57)</td>
<td>19.61 (8.67)</td>
<td>4.92*</td>
</tr>
<tr>
<td>Exercise Outcome Expectations</td>
<td>51.39 (4.91)</td>
<td>54.00 (4.70)</td>
<td>6.58*</td>
</tr>
<tr>
<td>Nutrition Outcome Expectations</td>
<td>31.41 (5.13)</td>
<td>32.32 (2.94)</td>
<td>8.87**</td>
</tr>
<tr>
<td>Fruits and Vegetable Intake</td>
<td>2.04 (0.79)</td>
<td>2.75 (0.84)</td>
<td>13.62**</td>
</tr>
<tr>
<td>Ideal Fruits and Vegetable Intake</td>
<td>3.64 (0.99)</td>
<td>4.11 (0.88)</td>
<td>11.25**</td>
</tr>
<tr>
<td>Nutrition Stages of Change</td>
<td>2.82 (1.28)</td>
<td>3.56 (1.34)</td>
<td>6.86*</td>
</tr>
</tbody>
</table>

* p < .05; ** p < .01

Marks, Sisirak, Chang, 2012
Organizational Culture...

• Supports health & well-being of people with I/DD and caregivers

• Links employee wellness programs to organizational outcomes
  – absenteeism
  – turnover
  – health care costs
  – workers compensation claims

• Healthier workforce linked to higher job satisfaction and performance.
Getting the Memo: It’s Everyone’s Job

- Lifelong culture of interdependency
- Expectations and the tyranny of none
- Power to determine health and health practices
HealthMatters Train the Trainer Workshop: Becoming a Certified Instructor

- 6-hour theoretically-driven workshop
- Strategies to teach exercise and nutrition classes and motivate people to achieve wellness goals
- Tools to evaluate changes in health
Signs & Symptoms Program: Early Recognition of Health Problems

- Increase continuity of care within day/residential CBOs.
- Instruct caregivers to observe early signs and symptoms of new or changing health concerns among people with I/DD.
Health Advocacy Program for Health Professionals

• Increase understanding of health care experiences and needs among adolescents and adults with I/DD

• Improve culturally relevant care
Peer to Peer

HealthMessages Program

• Teach people with I/DD to become Healthy Lifestyle Coaches with their Mentors to implement a 12-week HealthMessages Program for peers.
HealthMatters 4Kids: Today Counts

Diabetes Prevention Workshop

• Introduces health promotion and health advocacy for children and adolescents with I/DD
• Developed by Northpointe Resources in collaboration with HealthMatters Program at UIC.

Audience

Parents/Caregivers, Educators, and Healthcare Providers who support children with I/DD.
Scaling-Up Evidence-Based Programs

• Facilitate buy-in, fiscal accountability, and policy support from stakeholders

• Understand facilitators and barriers for scale-up

• Achieve widespread translation in CBOs for reach, effectiveness, adoption, implementation and maintenance of program