

## **Building Sustainable Health Promotion Programs for Persons with I/DD**

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Northpointe Resources, Inc., Zion, Illinois  
ARCA, Albuquerque, New Mexico  
Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago, Chicago, Illinois

Developmental Disabilities Nursing Association  
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May 9, 2009



### **Presenter:**

**Katie Brinkmeier, NorthPointe**

- Identify strategies for motivating and engaging adults with I/DD in a physical activity and health education program.
- Discuss ideas for supporting and training DSPs to teach core concepts relating to physical activity and nutrition to adults with I/DD.

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### **Purpose**

- Reviewing the processes of implementing a sustainable health promotion programs within community-based organizations.
- Discuss the value of Direct Support Professionals (DSPs) as health advocates within the health care team.

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### **Presenter:**

**Dina Donohue-Chase, NorthPointe**

- Review strategies for creating a climate that supports adults with I/DD to incorporate physical activity and healthy lifestyles into activities of daily living.
- Discuss the use of an organizational assessment for benchmarking and building capacity to sustain a health promotion program.

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**Presenter:**  
**Beth Marks, UIC**

- Review health status and health promotion needs of adults intellectual and developmental disabilities (I/DD) in community-based organizations (CBOs).
- Discuss the development and implementation of the Train-the-Trainer Program for promoting healthy behaviors and improving health status among people with I/DD.

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**Presenter:**  
**Leslie Hoelzel, ARCA**

- Discuss impact translating research to practice within CBOs.
- Present the need for statewide capacity-building for health promotion program sustainability.

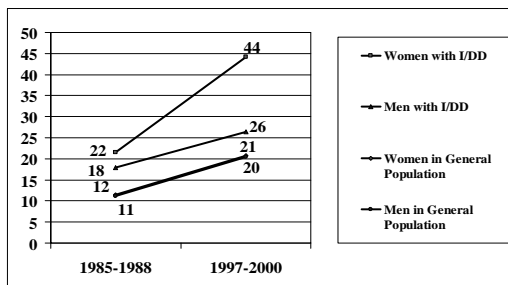
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## Demographics

- Prevalence rate of adults with I/DD 1.13% of the US non-institutionalized population.
- 641,000 adults age 60 and older.
- Projected increase of 90% to 1.2 million age 60+ by 2030.



## Prevalence of Obesity among Adults with I/DD by Gender



Yamaki (2002). Based on the National Health Interview Survey

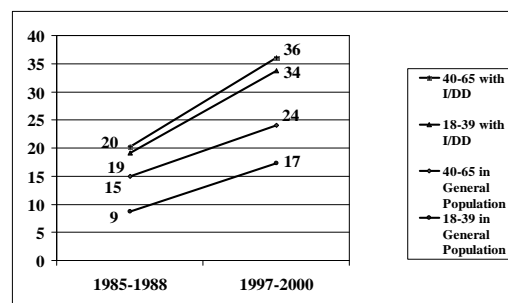
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## Health Behaviors

- For persons with I/DD, cardiovascular disease (CVD) is a common cause of death.
- Adults in the community have:
  - the highest CVD risk of all adults,
  - low levels of physical activity and poor food choices,
  - a high prevalence of being overweight or obese.



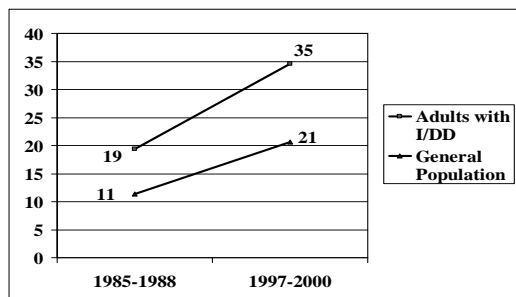
## Prevalence of Obesity among Adults with DD by Age



Yamaki (2002). Based on the National Health Interview Survey

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## Prevalence of Obesity among Adults with I/DD and the General Population



Yamaki (2002). Based on the National Health Interview Survey

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## Physical Activity and Nutrition

### Physical Activity

- ~ 10% of adults with I/DD engage in physical activity a minimum of three days a week.
- Most leisure-time activities are sedentary, such as watching television or listening to the radio.

### Nutrition

- 93% adults with I/DD living in the community have a high fat diet.\*
- 63% do not consume enough fruits and vegetables.



\* Draheim, et al. (2002).

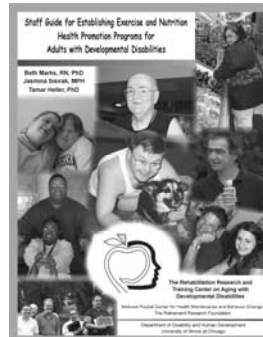
## UIC Exercise and Health Education Programs for Adults with I/DD

- University-based exercise and health education programs improve psychosocial and physical health (1998-2003).
- 5 year Train-the-Trainer study initiated in 2003 to address the need to increase physical activity and improve food choices in settings in which people work and live.



## Train-the-Trainer Workshop

- On-site, 1-day training for staff in CBO:
  - immediately before staff start UIC 12-week health promotion program
  - technical assistance provided during program
  - staff exit interview after 12-week program



## Research Aims and Objectives

- Broaden the generalizability of the UIC Health Promotion Program to increase physical activity and improve food choices among adults aging with I/DD in settings in which they work and live.
- Implement the Train-the-Trainer Program for promoting and maintaining healthy behaviors.



## Train-the-Trainer Program: Goals

Give staff trainers skills and strategies to:

- **Start** a 12- week physical activity and health education program for adults with I/DD
- **Teach** adults ways to increase physical activity and healthy food choices
- **Support** adults to make long-term lifestyle changes



## Theoretical Framework

- Transtheoretical Model of Behavior Change
- Social Cognitive Theory
  - Behavior change affected by:
    - perception of pros and cons
    - confidence in one's ability (self-efficacy)
    - perceived level of support for new behavior



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## 12-Week Program

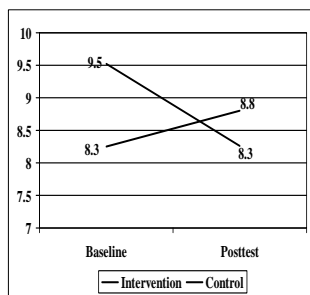
- 12-week program (36 classes taught by DSPs)
  - Individualized programs based on participants with I/DDs' needs and agencies' resources.
- 6 hours/week of exercise and health education
  - Health education classes: **Exercise and Nutrition Curriculum.**
  - Fitness classes: flexibility, aerobics, balance and strength (FABS).



\* Core concepts: self-determination, choice, self-efficacy, self-advocacy, rights and responsibilities

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## Pain



- Compared to the control group, participants in the intervention group reported less pain.

■ ( $F = 4.23$ ;  $p = .045^*$ )



\*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$

## Conclusion

- DSPs have a strong, positive impact in implementing tailored health promotion program.

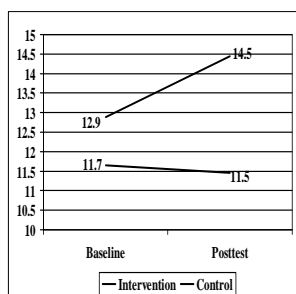
### Next Steps

- Develop Distance Learning course as an alternative to traditional training methods for staff.
- Examine environmental / organizational culture on organizations and individual readiness.



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## Self-Efficacy to Exercise



- Compared to the control group, participants in the intervention group reported greater self-efficacy to exercise.

■ ( $F = 27.57$ ;  $p = .000^{***}$ )

\*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$

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## NorthPointe Resources

Empowering individuals with disabilities to achieve their dreams.

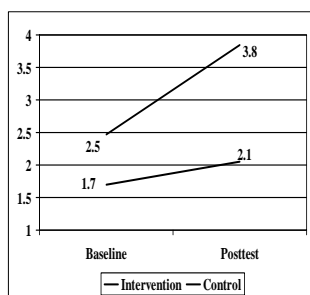
### Health Matters @ Northpointe

- Located in Zion, IL
- Serve over 400 individuals annually
- Vocational Division
  - Adult Day Services, Community Employment, Psychosocial Rehabilitation, Caregiver Connect, Home Based Supports
- Residential Division
  - CILA
  - 72D/In-Home CILA
- Business Division



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## Social/Environmental Supports (SES)



- Compared to the control group, participants in the intervention group reported greater SES for exercise.

■ ( $F = 8.17$ ;  $p = .006^{**}$ )

\*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$

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### Health Matters @ Northpointe Health Status and Disability

A large proportion of persons who are in **bad health** end up with a **disability**.

A large proportion of **persons with disabilities** end up with **bad health**.



## Health Matters @ Northpointe

### Introduction of Health Promotion

- Initial contact with UIC
- Curriculum Introduced
- Access to Community Fitness Center
- Key staff trained
- 6 consumers completed initial program
- Positive Results
  - Decreased cholesterol, pain, barriers to exercise
  - Increased flexibility, aerobic endurance, balance, strength, self-confidence



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## Health Matters @ Northpointe

### It's Everyone's Job

- Health and Wellness Facilitator hired
  - Working in individual's homes
  - "Hands-on" training in health promotion activities for individuals and direct support staff
- Toolkits
  - Thera-Bands, hand held weights
  - Exercise Videos
  - Jump Ropes
  - NorthPointe "Workout Mix" CD
  - Community Resource Guide

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## Health Matters @ Northpointe

### Creating a Sustainable Program

- On-going 12-Week program
  - UIC curriculum
  - Focused on un-duplicated individuals
- Additional Health Promotion Opportunities offered
  - Expanded classes in day program setting
  - Additional recreational opportunities
  - Opportunities for education and physical activity

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## Health Matters @ Northpointe

### Health Promotion "Road Blocks"

- Transportation
- Communication
- Budget constraints
- Agency-wide support
- Perceived time commitment
- Consistent Support
- Carry-over to all parts of individuals lives



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## Health Matters @ Northpointe

### Expanding Opportunities

- Staff Training
  - All staff trained at hire
  - Additional Train-the-Trainer Opportunities
- Individual Service Plans
- Job Descriptions
  - General statement in all
- Satisfaction Surveys
- "Health Matters" developed



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## Health Matters @ Northpointe

### Overcoming the Roadblocks Role of the DSP

- Leading by Example
- Establish Routines
- Consistency
- Assist with meal planning/grocery shopping
- Planning community outings
- Part of development and implementation of Individual Service Plans
- Close relationships

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## Health Matters @ Northpointe

### Overcoming the Roadblocks Strategies for Engaging Individuals



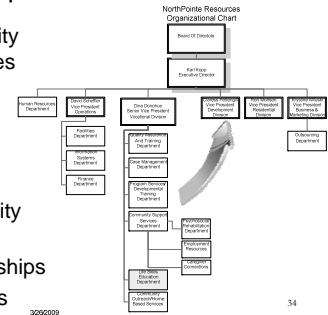
- Consider Individual Factors
  - Knowledge, attitudes, abilities
- Attitude
- Approach
- Opportunities
- Connections
- Reinforce positive choices
- Do it together
- PRAISE, PRAISE, PRAISE
- Organizational Commitment

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## Health Matters @ Northpointe

### Grassroots Initiative Expanded

- Expansion To Community Living/Residential Homes
  - Train-The-Trainer
    - DSPs Trained
- Expanded Day Service Opportunities
- Partnered with community fitness centers
  - Reduced Memberships
  - Training at Centers



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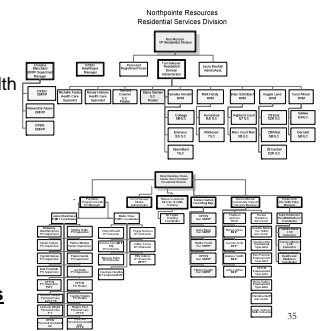
## Health Matters @ Northpointe Background

- The Realities
  - Living Longer, Desire To Age In Place, Secondary Health Conditions
- The Challenges
  - State Policy, Access, Resources
- The Response
  - Health Education, Nutrition and Exercise
  - Partnerships and Outreach

## Health Matters @ Northpointe

### Grassroots Outcome

- Improved DSPs skills
  - Knowledge
  - Confidence
- Positive Psychosocial & Health Indicators
  - Reduced cholesterol
  - Increased ROM
  - Weight Reduction
- Individuals
  - More Active
  - Expanded Opportunities
  - Self Efficacy
- **Declining Health Behaviors over time**

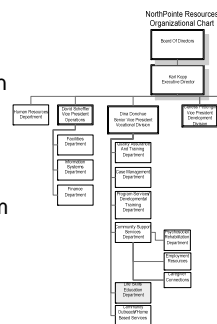


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## Health Matters @ Northpointe

### Grassroots Initiative

- United Way Grant
  - Funded a FT Position
- Partnered with UIC
  - Consultation
  - Training
- Adopted UIC Curriculum
  - Initiated Curriculum through day services



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## Health Matters @ Northpointe

### Suspected Barriers to Project Sustainability

- Community Living Counselors
  - Overlay of Responsibilities
- Top Down Commitment
- Organizational Resources
- Organizational Culture
- Turnover
- Illinois State Policy and Funding



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## Health Matters @ Northpointe

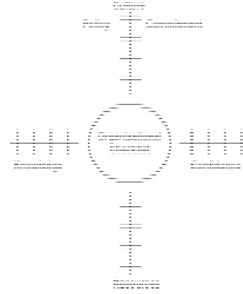
### Sustainability Assumptions

- Changes sought in community organizations will be of little value unless they can be sustained
- Few changes will last unless the culture is modified to support desired goals
- Changing organizational culture requires the continuing commitment of a significant number of organizational members
- Systematic culture change is more than periodic random offerings
- Change requires a comprehensive, systematized and continuing revision of cultural influence mechanisms

The Corporate Culture Sourcebook. Amherst, MA: Human Resource Development Press 37

## Health Matters @ Northpointe

### Organizational Health Promotion Capacity Checklist "Getting the Memo"



- **Strategically Balanced Approach**
  - ✓ Culture
  - ✓ Confidence
  - ✓ Knowledge
  - ✓ Resources

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## Health Matters @ Northpointe

### Organizational Health Promotion Checklist "Getting the Memo"

- Develop and test an Health Promotion Capacity Checklist for Community-Based Organizations (CBO) to ensure that all staff have the capacity to implement health and wellness activities for people with I/DD
  - Management
    - Advance organizational change by developing sustainable program
    - Create a "Culture of Wellness"
  - Participants
    - Increase health awareness, skills and abilities
    - Break down barriers to healthy lifestyles

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## Health Matters @ Northpointe

### Organizational Checklist Organizational Capacity

- **Culture:** Leaders, managers and staff enable and support health promotion practice and values are practiced.
  - Commitment – Employees believe in and advocate for health promotion
  - Policy – Vision, mission, and policies to support health promotion
- **Knowledge:** Employees understand fundamental principals and strategies of health promotion
- **Confidence:** Employees are able to implement health promotion activities
- **Resources:** Employees have resources to promote health among adults with I/DD

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## Health Matters @ Northpointe

### Organizational Health Promotion Checklist "Getting the Memo" 1 Year Project ---- 6 Step Process

- 1) **Community Entrée**  
Met with key stakeholders to discuss interest in project  
Obtain Institutional Review Board approval
- 2) **Issue Identification and 3) Prioritization of Issues**  
Recruited and consented participants for focus groups  
Convened focus groups with key stakeholders  
Developed Organizational Capacity Checklists
- 4) **Strategy Development**  
Pilot tested the Checklist for reliability and construct validity  
Entered, analyzed, and presented the results of the Checklist to key stakeholders  
Discussed further the top priority issues, how they affect consumers and staff, and plans to resolve issues
- 5) **Implementation and 6) Transition**  
Discuss Results and/or progress  
Design Making on the next steps



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## Health Matters @ Northpointe

### Organizational Capacity Culture: Commitment and Policy

- Perceptions on organization support for efforts to promote health.
- Items:
  - Value health promotion in organization
    - Vision, Mission
  - Policies and programs support health promotion
    - Shared responsibility, handbooks, memberships to gyms
  - Strategic priorities align with health promotion
  - Leaders and managers are supportive
  - Communication is clear throughout organization, i.e., job descriptions, performance reviews
    - Did everyone "Get the Memo"

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## Health Matters @ Northpointe

### Organizational Capacity

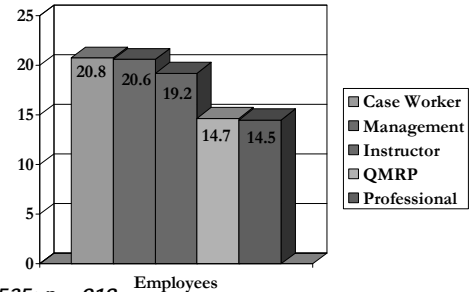
Knowledge

- Employee's perceptions about their capacity to provide health promotion to adults with I/DD (i.e., healthy food choices, fitness)
- Items:
  - Health risk factors
  - Importance of health promotion and health promotion strategies
  - Inclusion of personal preferences, participation, resources

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## Health Matters @ Northpointe

### Confidence Doing Health Promotion Activities By Employees



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## Health Matters @ Northpointe

### Organizational Capacity

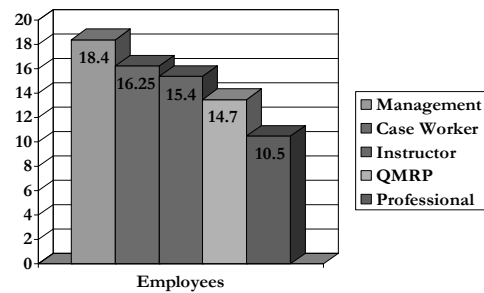
Confidence

- Teaching and Doing Health Promotion Activities
  - Staff's confidence as to whether they can do specific types of health promotion activities
  - Staff's confidence that they can teach people with I/DD to do specific types of exercises



## Health Matters @ Northpointe

### Available Resources By Employees



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## Health Matters @ Northpointe

### Organizational Capacity

Resources

- Perceptions regarding agency resources for health promotion activities
- Items:
  - Time, equipment/resources, support from manager and co-workers to do health promotion activities
    - Fitness related supplies, cooking utensils, recipes
  - Trainings on health promotion provided to people with I/DD and staff
  - Health promotion activities available for people with I/DD and staff
  - Access to financial and community resources for activities
    - Gym membership, money to purchase healthy food

## Health Matters @ Northpointe

### Organizational Community Checklist Conclusions

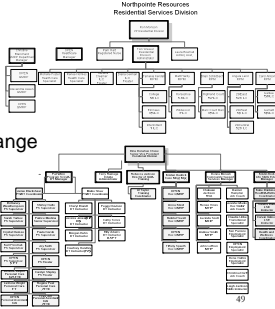
- The Organizational Checklist can assist management in CBOs to **develop and implement health promotion programs** to clients with I/DD and their employees.
- Future use of the Checklist aimed at assisting management to **conduct internal and external benchmarking** – comparisons within and across organizations.
- The Checklist can be used to **develop strategic plans** related to health promotion goals and objectives aimed at creating a culture of health and wellness (e.g., policies, health promotion activities).

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## Health Matters @ Northpointe

Organizational Health Promotion Capacity Checklist  
Immediate Outcomes

- Mission and Vision
- DSP Staff Trained
  - DSP Curriculum Training
- Residential Health Promotion Facilitator
  - Grant Funded – Systems Change
- Health Matters Toolkits
- Organizational Structure
  - Staff Wellness
  - Corporate Fitness Challenge
  - Reduced Memberships
- Day Services Expansion



## Systems Effects on Translating Research into Practice at ARCA


- Socio-ecological models view context – changing interpersonal, organizational, community, and public policy approaches to produce changes in individuals, eg. environments shape behavior. (McLeroy et al).
- Hierarchy – Vertical (up and down care systems)
- Horizontal (across statewide network)

McLeroy, Bibeau, Steckler and Glanz (1988).

## Health Matters @ Northpointe

Next Steps  
Advancing Health Matters


- Evaluate construct validity of the Health Promotion Capacity Checklist with larger sample
  - Conduct multi-level analysis across different houses (e.g., turnover rates, health status)
- Analyze data
  - Collected 3 months after administration of the *Health Matters: It's Everyone's Job* training to 160 CBO employees
- Organizational Structure
  - Revise job descriptions, policies and procedures and financial reallocation



## Sample Socio-ecological Model

Model: Oregon Department of Health


## About ARCA



- New Mexico's largest private non-profit organization providing comprehensive community-based services to individuals with I/DD, since 1957.
- Primarily metropolitan (PWS rural and tribal)
- 630+ workforce; 77% DSPs
- Serving 587 babies, children and adults across their life-span.
- Albuquerque: <http://www.ARCASOpeningDoors.org>

## ARCA Activities Fall 2005- Date

Achieved fidelity with the UIC Health Promotion program with key personnel in place resulting in measurable health improvements with technical assistance from UIC.



Provided the program to 152 persons with I/DD; trained 35 ARCA personnel (DSPs and nurses) as instructors.

ARCA's program expanded vertically and horizontally.

## Before and After Case Study



Source: March 2009 DDNA Newsletter

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## Sustainability – Where Do We Go from Here?

- Fully integrating this model within services.
- Helping DSPs learn to use the framework to capitalize on naturally occurring circumstances and teachable moments.
- Better alignment within systems/networks (ARCA training) (building a grassroots cadre of proponents).
- Advocacy with policy makers.
- Encouraging/supporting proven **Drivers:** Persons, Attitudes, Funding, Best Practices.

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## Sample ARCA Data Set of Graduate Outcomes Year-End (2007/08)

- 61% lost **weight**, changed **body composition**
- 69% increased **HDL**
- 37% decreased **LDL**
- 54% decreased their **TC/HDL** (ratio-risk of heart disease)
- 59% decreased their **Glucose**
- 53% improved on their **6-Minute Walk**
- 52% improved on the **Sit-to-Stand**
- 50% improved on the **YMCA Bench Press**
- 43% improved on the **Get-Up-and-Go**
- 40% increased **Behind-the-Back (Apley test)**
- 31% increased **Behind-the-Back (Apley test)**
- 59% improved on the **Sit-and-Reach**

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## Statewide Outreach “practicing to do good and planning to do better”

- Partnered with the Con Alma HEALTH Foundation (2008) to train staff at nine (9) New Mexico organizations/Navajo Nation entity serving persons with I/DD.
- Locations: Clovis, Roswell, Artesia, Alamogordo, Albuquerque, and Gallup (2).
- Trained 44 staff in residential/day programs.
- Two programs cancelled due to community audits.

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# THANK YOU!

## Questions and Comments

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