On Your Mark:

A CBPR Partnership on Obesity in Children with Disabilities

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Lessons Learned:
Engaging Diverse Communities in Obesity Research

National Institutes of Health
April 29, 2013
Project significance

The overall purpose of this project is to establish a regional academic-community partner network to identify community-based research priorities and develop a long-term collaborative agenda to 1) reduce obesity risk and 2) promote long-term health in school-age children with developmental disabilities (DD) such as autism and intellectual disabilities.
R13HD063168 on Obesity in Children with Disabilities
United Cerebral Palsy of Central PA and Temple Univ. School of Medicine

- **History of our partnership**

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Project specific aims

1) Build a **strong working relationship** and a set of research goals focused on community priorities in addressing and reducing health-disparities through a series of inter-related meetings, workshops and community forums.

2) **Provide health education** about the problems related to childhood obesity in a manner that is sensitive to the community’s perceptions of their experiences, e.g. stigma, regarding this area of health disparities.

3) Outreach to the community to **identify stakeholders’ areas of interest** in addressing disparities in obesity and provide expert consultation to the community about research-related topics that they identify as important.

4) Implement a **Memorandum of Understanding** between Temple University and one or more community organizations in the network for the purpose of developing a CBPR agenda on health disparities in obesity for this population.
Children with functional limitations in physical activity are approximately 2.3 times more likely to be overweight than children without such limitations (Minihan, Fitch and Must, 2007). Heightened risk factors include medication use, unhealthy diets, mobility limitations, family stressors associated with the financial strain of having a child with developmental disabilities, and lack in many schools of specialized resources to tailor nutritional or physical activity-related interventions.
Project partnership structure

“Umbrella” organization re children: Capital Area Intermediate Unit

Two advocacy organizations:
- UCP of Central Pennsylvania
- ARC of Cumberland County

Two county agencies:
- Dauphin County I/DD
- Cumberland-Perry Counties I/DD

One academic affiliate:
- Temple University Center for Obesity Research and Education (CORE)
Identifying key stakeholders

The project partners were tasked with identifying members for the Advisory Board, approximately 3-4 from each partner.

Advisory Board included the Medical Director of the Commonwealth’s Office of Developmental Programs
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- County and Commonwealth representatives

Susan Carbaugh - Cumberland County IDD, Director
Joy Hafer - Dauphin County IDD
Shirley Keith-Knox - Dauphin County IDD, Director
Jill Morrow-Gorton - Medical Director, PA Office of Developmental Programs
James Richards - Cumberland County IDD
Advocacy agency staff

Cindy Adams - Arc of Cumberland County
Winnie Black - Arc of Dauphin/Lebanon Counties
Barry Claypool - UCP Central PA
Deb Eslinger - UCP Central PA
Vincent Gurreri - Arc of Cumberland County, Director
Barb Jumper - Arc of Dauphin/Lebanon Counties, Director
Kathy Seiderer - UCP Central PA
Lucy Zander - Arc of Cumberland County
Community volunteers and family members

Brian Keefer
Bill Schultz
Fran Shade
* Maggie Barbush
* Abby Zonarich
* Elizabeth Zonarich
* Students age 11 - 18
Educators and therapists

Donald Dupes - High school teacher
Elaine Karl - High school teacher
Suzanne Knouse - Elementary school teacher
Cheryl Park - Capital Area Intermediate Unit
Amy Swartz - Early intervention director
Kathy Zonarich - Physical therapist
Consultants

Myles Faith, PhD - Associate Professor of Nutrition, University of North Carolina

Aviva Must, PhD - Professor and Dean, Tufts University Public Health and Professional Degree Programs

Ronald Williams, MD – Internist and Pediatrician, Penn State Hershey Medical Center
Ready Set Go for Health website

Ready Set Go for Health... taking steps towards a healthier future for individuals with disabilities and their families.

It is widely recognized that the earlier in life that children are introduced to exercise and nutritional guidelines, the more likely they will carry those habits into adulthood.

The Ready Set Go for Health website is the primary focus of the READY (Resources for Exercise Activities & Diet for You) Project established through a joint Temple University/UCP Central PA initiative which aims to reduce the risk of obesity in children with disabilities. The initiative is funded through a grant by the National Institutes of Health (NIH R01 HD48898).

The project was set up by a volunteer group, with the help of several community members who learned about the READY project at a grant-sponsored Community Forum. The group met once a quarter to help develop a website to provide children with disabilities and their parents with resources they can use to lead healthier lives.
Assessing the community’s priorities

At Community Forums

Most successfully, using a questionnaire distributed by the CAIU and other project partners to parents. The survey was available on the internet (SurveyMonkey) as well as in hard copy.
Results from family surveys:

- 150 valid responses from the 3-county area
- 40% of the children were overweight
- 80% of the children had intellectual disabilities
- 30% of the children had physical disabilities
- 48% of the children were girls
Importance of & satisfaction w/ health promotion

Parents’ ratings of nutrition and diet opportunities

Parent buy affordable fresh fruit and vegetables:
Definitely important: 83%  Definitely satisfied: 40%

Child learn about healthy food choices and amounts:
Definitely important: 72%  Definitely satisfied: 44%

Parent learn about healthy food choices and amounts:
Definitely important: 70%  Definitely satisfied: 56%

Parent improve shop/food prep to help w/ healthy weight:
Definitely important: 64%  Definitely satisfied: 52%

Parent learn how much child should weigh:
Definitely important: 62%  Definitely satisfied: 59%

Child learn about how much he or she should weigh:
Definitely important: 59%  Definitely satisfied: 46%
Importance of & satisfaction w/ health promotion

Parents’ ratings of physical activity opportunities

Affordable individual or group exercise for child:
  Definitely important: 67%*   Definitely satisfied: 19%

Child learn about kind and amount of physical activity:
  Definitely important: 59%   Definitely satisfied: 20%

Parent learn about kind and amount of physical activity:
  Definitely important: 59%   Definitely satisfied: 31%

Affordable team sports for child:
  Definitely important: 54%   Definitely satisfied: 24%

*Significantly more important if child was underweight (16% of sample) or overweight/obese (36% of sample). Interest in improving phys. act. was less if child was underweight (58% said “yes”) than normal/overweight/obese (82% said “yes”).
Major challenge: Involving families in forums

Although we tried various formats, days and times, seasons, venues, child care and refreshments were provided and advertised, expert speakers were presenters, health fair format was featured, events were advertised well in advance and distributed through many channels to the community.
Partnership evaluation

- Written quantitative evaluations and reflection time after each Board meeting
- Community Forum written evaluations
- Annual reports to County agencies
- RO3 proposal progress
Questions, comments?

Thank you!